

National
Dementia
Office



THE ALZHEIMER
SOCIETY *of* IRELAND

**Submission to the Department of Health on
Deprivation of Liberty Safeguard Consultation**

March 2018

1.Introduction

The Alzheimer Society of Ireland (ASI) and the National Dementia Office (NDO) welcome the opportunity to make a joint submission on the Deprivation of Liberty Safeguard Consultation. Our position is informed by the overarching principles of the National Dementia Strategy (NDS), that of personhood and citizenship. These principles are to enable people with dementia to maintain their identity, resilience and dignity, by recognising that they remain valued, independent citizens who, along with their carers, have the right to be fully included as active citizens in society. Once in force, the proposed legislation will inform policy and practice, and directly affect the lives of tens of thousands of people with dementia and their families in relation to their autonomy, dignity and human rights.

The draft heads state the legislation applies to older people, persons with disabilities and people with a mental health illness. Firstly, this implies that there is a question of mental capacity for only three groups in society, which is clearly discriminatory. Secondly, this is counter to the principles set out in the Assisted Decision Making (Capacity) Act where there is an assumption of capacity, supporting decision making and wherever possible respecting the person's expressed wishes. The principles and approaches of the ADM Act need to be mirrored in the Deprivation of Liberty legislation.

Before progressing to comments on the Draft Heads of Bill it is important to put the legislation in context in terms of dementia. There are currently an estimated 55,266 people living with dementia in Ireland and if current trends continue this number will rise to 95,863 people by 2031 (O'Shea, Cahill and Pierce, 2016). While dementia is not a normal part of the ageing process, age is the main risk. Accordingly, the prevalence of dementia is very much connected to Ireland's ageing population. There is however also a cohort of younger people living with dementia, those aged under 65 years. One in 10 people diagnosed are in this group. People 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.

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 for the person 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).

Ensuring that a person with dementia has autonomy to make decisions and that they are central to decision-making is now both ethically and legally important. Although it is obligatory to protect a person with dementia from seriously harmful consequences, it is equally obligatory to respect his/her role in decision-making. This is echoed by people with dementia themselves where the Irish Charter of Rights for People with Dementia states that people with dementia should be allowed to exercise their remaining capacities for choice, consistent with their values, wishes, will and preferences and cultural expectations (Irish Dementia Working Group and the Alzheimer Society of Ireland, 2016). This enables a person to be independent and to live with dignity.

2. Comments on Definitions

Clarity of certain definitions in the Draft Heads of Bill and associated consultation paper is required. A clear definition of Deprivation of Liberty is needed; one which sets out its scope. For example, does it apply to control over care, treatment, movement, medication management and/or activities of daily living? This explanation extends also to the terminology used throughout regarding what is meant and covered in 'under continuous supervision and control'.

Also clear instruction on when deprivation of liberty applies needs to be set out in the legislation. For example, does it apply when the person has not consented; when the person assents but does not clearly give a statement of consent; when the person is deemed not to have mental capacity and/or when their will and preferences are unknown? The Assisted Decision Making (Capacity) Act places the onus on the intervener to give effect to the past and present will and preferences of the relevant person, in so far as that will and those preferences are reasonably ascertainable. This approach must be mirrored in the Deprivation of Liberty legislation. The focus should be on the potential of the person with dementia to be fully realised during all stages of their condition; for them to be seen as an asset and as citizens with inalienable rights that must be protected (Genio/NDO, 2017). Indeed, those bodies and individuals responsible for the care and treatment of

people with dementia will become accountable for the respect, protection and fulfilment of their human rights and adequate steps should be adopted to ensure this is the case (Charter of Rights for Persons with Dementia, 2016).

In relation to the relevant facility in which the legislation applies, the definition of nursing home as defined in section 2 of the Health (Nursing Homes) Act 1990 should be included. Clarity is also required on whether the legislation applies to those in respite care e.g. people who are temporarily living under continuous supervision and control and not free to leave. Or those people who experience a delay in being discharged from an acute hospital and may remain in that setting for months and sometimes years. Reasons for this can be complex but the acute setting is effectively where the person lives under continuous supervision and control. It is also expected that if good quality and better integrated primary and community care services were in place, demand on acute hospitals would almost certainly be reduced as unnecessary and costly admissions to hospital could be avoided (Genio/NDO, 2017).

3. Training and Education

Depriving someone of their liberty can have a profound impact on the individual. It involves complex processes and must ultimately be viewed as a last resort. The individuals' rights should be respected at all times and clear guidance is required for health and social care professionals/clinicians who will be involved in this process.

People with dementia have the right to health and social care services provided by health and social care professionals (HSCPs) who have had appropriate training on dementia and human rights to ensure the highest quality of service. The draft legislative provisions places an onus on clinicians and other HSCPs and service providers to support people with dementia in terms of the decision they make to enter or remain in long- term care. It is important to be aware that the mental capacity of a person with dementia can change over time both in the short and long term. This means that HSCPs, particularly those in nursing homes, have a significant responsibility to support people with dementia to make person-centred decisions as their mental capacity changes.

We welcome the statement in the accompanying notes that a campaign around decision-making arrangements will be undertaken to inform people and their families of their rights. In addition to this is that timely, appropriate and accessible information is provided to people to inform choices and decision-making. Similar guidance is also required for professionals who will be involved in driving the decisions that need to be made and to ensure appropriate

implementation.

Specific training relating to the new legislation will need to be developed, and HSCPs will require in-depth understanding of how this legislation impacts on people with dementia, what their responsibilities are, on appropriate procedure, and how they can support the latter to make a person-centred choice, centring on respect for identity and dignity. The codes of practice developed for this legislation will be important in terms of ensuring it protects people's rights and provides appropriate guidance for health and social care professionals.

4. Advocacy

Adequate support of carers is crucial as it also supports the person with dementia, as highlighted in the De-Stress study (Brennan et al., 2017), which was part-funded by the ASI. Family carers need to be viewed and included as partners in the care of the person with dementia, working with formal care providers. Family carers need to be supported in understanding the meaning and implication of the new legislation relating to Deprivation of Liberty. In this regard, clear and accessible information is crucial and the proposed campaign around decision-making arrangements to inform people and their families of their rights will be essential.

People with dementia residing in long-term care may have very limited opportunity to challenge a decision relating to them without access to personal advocacy. In the UK access to an Independent Mental Capacity Advocate is mandatory for deprivation of liberty cases. It is worrying that there is not a single mention of an advocate in the Draft Heads. An independent advocacy or advocate service is needed to ensure that individuals' rights are protected and all practicable steps and possible alternatives have been exhausted before progressing to deprivation of liberty; and where the person's will and preferences, when they are known, are respected. This type of service will need to be properly resourced and regulated.

Another specific concern relating to Head 3, Person's Capacity to Make a Decision to Live in a Relevant Facility in Advance of an Application to enter the Relevant Facility, is how the individuals' voice is being heard in relation to admission/detention. This is unclear, nor is it clearly set out how their rights are being protected and who and in what way these are being advocated for.

5. Strengthening Community Care Alternatives

Appropriate community resources are also very relevant specifically when deprivation of liberty must be considered only as a last resort where all alternatives have been exhausted. It should not be viewed as a routine part of admission to long-term care. The allocation of resources for older person's services do not reflect the priority to enable older people, including people with dementia, to remain living at home nor does it support the principle of personhood as set out in the NDS. The current review of home care which is underway within the Department of Health should strengthen people's access and entitlement to community care. However, the current situation is that there are gaps in the continuum of services and supports for people with dementia in the community and it has been found that community support services for people with dementia and their carers are under-developed and fragmented (Cahill et al., 2012). This has implications for the Deprivation of Liberty legislation in that alternatives to long-term residential care may not be a real choice for many people currently living with dementia in Ireland and is counter to the preferred choice of many people with dementia to remain living at home for as long as possible (Donnelly et al., 2016).

Within the NDS, Integrated Services, Supports and Care for People with Dementia and their Carers has been identified as a priority area of action, with a specific action for the HSE that consideration will be given to "how best to configure resources currently invested in home care packages and respite care so as to facilitate people with dementia to continue living in their own homes and communities for as long as possible and to improve the supports available for carers" (Department of Health, 2014). Evidence emerging from the HSE's and Genio's work to test the feasibility of an individualised service model aimed at improving the range and quality of home care services and community based supports for people with dementia shows that it is possible to provide flexible, personalised and high levels of support to people with dementia in their own homes. This sentiment has long been echoed by the ASI who has similar experiences in their support for people with dementia and family carers. In this context, the development of this legislation seems counterintuitive – we are formalising and legalising a path of action that should perhaps not be used at all, or at least very rarely.

If a person with dementia decides not to enter long-term care or wishes to leave long-term care to return home, it is essential that key supports and services are in place to support them to remain at home in the community. Clear referral pathways are required for people

with dementia, and an integrated dementia care pathway approach is required to enable service providers and supports for people with dementia to work in a collaborative and coordinated way, as set out in the NDS.

The NDS outlines a priority action within primary care services of a care coordinator to play a key role in coordinating the care of each person with dementia and promoting their continuity of care. There is potential that this role could be a crucial support in facilitating the person with dementia who chooses to leave care, or indeed not enter long-term care. This role, of a single point of contact for the person with dementia, would help to coordinate individual care plans and assist people with dementia to navigate complex care pathways. It would facilitate a collaborative management plan for individual dementia care and an integrated approach to dementia care, and is recommended as an efficient and effective measure (ASI, 2018). The role of this single point of contact would contribute to promoting a system of strategic dementia care that comprises interlinking and integrated supports and a multidisciplinary response by primary and secondary care and community services. The National Dementia Office, with a multi-disciplinary working group is working towards developing a job description for this role based on available national and international evidence.

Community care should be viewed as an integral part of the health and social care system in itself and needs to be developed in relation to this proposed legislation. Community care can prevent people entering the acute system and delay admission to long-term care.

6. Use of Restraint

The issue of restraint often arises in the context of dementia either because it is seen as a way of protecting the person or because of concerns about the safety of others. Often the person cannot give informed consent given the advanced nature of dementia, which is the reality for many people with dementia living in long term care. Restraint in such circumstances, where consent cannot be given, may be experienced as highly demeaning and distressing.

The most obvious form of restraint is physical restraint involving force or use of specific pieces of equipment. Environmental restraint is limiting a resident to a particular environment (e.g. their bedroom) or excluding the person from an area to which they want to go (e.g. locking doors to prevent the person from going outside). Chemical restraint, in which drugs are used to restrict the freedom or movement of a person, or in some cases to sedate a

person, can prevent people with dementia from exercising their decision-making capacity and making choices in relation to their care. It is the official policy of the HSE to ensure that restraints are not used in the care of older people in residential care and community hospital settings. However, it is acknowledged, that in a small number of very exceptional cases and as a last resort, time limited restraint may be considered as part of the residents care plan. For the person, the use of restraint and all decisions around this must be clearly recorded and incorporated into the person's care plan, setting out the decision-making/reason, use and form of restraint being applied. Who does this, how is it supervised and where is it reported is unclear from Head 10 of the Deprivation of Liberty Draft Heads of Bill. In addition, by focusing solely on chemical restraint the Draft Head of Bill implies that other forms of restraint are permissible.

A definition of restraint is required. An example for the HSE policy on restraint is: "Any physical, chemical or environmental intervention used specifically to restrict the freedom of movement – or behaviour perceived by others to be antisocial – of a resident designated as receiving care in an aged care facility. It does not refer to equipment requested by the individual for their safety, mobility or comfort. Neither does it refer to drugs used – with informed consent – to treat specific, appropriately diagnosed conditions where drug use is clinically indicated to be the most appropriate treatment (Nay and Koch 2006). Adapted

7. Transitional Arrangements and Review Decisions

This proposed legislation places a high level of responsibility on the 'person in charge' of the care facility to assess whether the person lacks capacity to make a decision to continue to live in the relevant facility, to assess whether capacity will fluctuate in the future and to notify people specified by the person with dementia and, where necessary, to contact the Director of the Decision Support Service and request that an appropriate person be assigned to the person with dementia to make the application on their behalf. This responsibility will have significant implications for care facilities and on the 'person in charge'.

If a person with dementia decides they wish to leave long-term care and return home, there needs to be clarity about the process and timeline in terms of this decision being made. It will be important that the family carer is informed of the transitional process and how such arrangements will be made. This is also important for the review of admission decisions, and in both cases such information should be clear and accessible.

For people with dementia who do not have a supportive family or who do not have a decision-making arrangement in place, there is no consideration given to how the person's voice will be heard and who will advocate for them. It is imperative that they are assigned an independent advocate who can support their rights so they can make an informed person-centred decision. There is a crucial need for an independent advocate to support the review process and transitional arrangements, and ensure that all practicable steps and possible alternatives are exhausted when Deprivation of Liberty is being considered.

We also have concerns relating to Head 5 - the emergency detention - it seems to say a single "person in charge" can activate a "temporary admission decision" and seek medical advice (again from a single medical practitioner) within 72 hours. This situation would be unacceptable. For example, under the Mental Health Act, 2001, two independent, fully registered doctors have to examine a person within 24 hours of an application by a concerned person for involuntary admission.

The Assisted Decision Making (Capacity) Act adopts a functional approach to capacity and adherence to will and preferences rather than best interests. This approach must be mirrored in the Deprivation of Liberty legislation, and will and preferences of the person with dementia should be upheld. This focuses decision-making on the guiding principles of autonomy, dignity, privacy and integrity, which are designated rights for people with dementia.

8. Documentation and Records

There will need to be clear and thorough documentation maintained in relation to values, wishes and preferences of people with dementia. Documentation and record keeping should reflect good practice under the legislation. This applies to application and assessment forms, and should place the person with dementia at the centre of decisions. Some key questions should include, how is the request to leave long-term care managed in practice and on paper? Are people with dementia given the choice or asked at certain time points if they wish to remain in or leave long-term care? Are these responses recorded as part of the individuals' will and preferences? This proposed legislation should act as a tool to progress human rights for people with dementia and impact positively on the ground for people living with dementia.

9. Summary Views

This joint submission on the Deprivation of Liberty Safeguard Proposal by the National Dementia Office (NDO) and the Alzheimer Society of Ireland is strongly informed by the principles of personhood and citizenship, as set out in the NDS. People with dementia have the right to be provided with accessible information and necessary supports to enable them to exercise their right to participate in decisions and policies which affect them (Charter of Rights for Persons with Dementia, 2016).

The Deprivation of Liberty Draft Heads of Bill raises a number of concerns that need to be effectively addressed. Foremost deprivation of liberty must be viewed as a last resort when all possible alternatives have been exhausted and must not be viewed as a routine part of admission to long-term care. Other concerns include but are not limited to:

- **Definitions:** There is a need for clarity of certain definitions in the Draft Heads of Bill and associated consultation paper, particularly relating to terminology, such as ‘supervision and control’; whether the legislation applies to those in respite care, those awaiting a suitable relevant facility place elsewhere, or transiently transferred out of the relevant facility; and when deprivation of liberty applies.
- **Training and education:** Specific training relating to the new legislation will need to be developed, and HSCPs will need in-depth understanding of how this legislation will impact on people with dementia. The draft legislative provision places an onus on clinicians and other HSCPs and service providers to support people with dementia.
- **Advocacy:** Family carers need to be supported in understanding the practical meaning and implication of the new legislation. An independent advocacy service is needed to ensure that individuals’ rights are protected and all practicable steps and possible alternatives have been exhausted.
- **Community care alternatives:** Availability of appropriate community resources are crucial, particularly given that allocation of resources for older person’s services do not reflect the priority to enable older people, including people with dementia, to remain living at home nor does it support the principle of personhood as set out in the NDS.
- **Restraint:** If the proposed legislation is to be implemented, there will need to be a

commitment to minimising the use of restraint, along with discussion and understanding among all key stakeholders about how this can be implemented.

It is of utmost importance that the person with dementia is supported in decisions relating to their care, that capacity is assumed and a decision is based on a person's values, wishes and will and preferences. Good practice for dementia care should emphasise personhood, the strengths and abilities of the person with dementia, and should strongly support their voice.

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About the National Dementia Office

The National Dementia Office (NDO), Health Service Executive (HSE) was established to oversee the implementation, monitoring, and ongoing evaluation of the National Dementia Strategy (NDS) which was published at the end of 2014.

The vision of the office is that people with dementia and their family carers receive the supports and services they need to fulfil their potential and to maintain their identity, resilience and dignity as valued and active citizens in society.

For more information contact: dementia.office@hse.ie

About the Alzheimer Society of Ireland

The ASI is the national leader in advocating for and providing dementia-specific supports and services and each year the organisation provides more than one million hours of community-based dementia-specific care throughout Ireland.

The ASI provides the following services:

- National Helpline
- Social Clubs
- Support Groups
- Day Care Services
- Home Care
- Dementia Advisor Service
- Mobile Information Bus

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