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THE ALZHEIMER
SOCIETY of IRELAND

Position Paper on the Assisted Decision Making (Capacity) Act 2015

ASSISTED DECISION MAKING (CAPACITY) LEGISLATION

This position paper gives an overview of the Assisted Decision Making (Capacity) legislation and outlines the key structures and elements of the legislation that will impact on policy and practice for people with dementia and their families.

The Alzheimer Society of Ireland welcomes this capacity legislation. This legislation will provide the legal guidance to the autonomy and dignity of the person with impaired capacity. Ensuring that a person with dementia has his or her autonomy to make decisions respected 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 or her role in decision making. People with dementia should be allowed to exercise their remaining capacities for choice, consistent with their values, wishes, will and preferences and cultural expectations. This enables a person to be independent and to live with dignity.

POSITION PAPER

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Executive summary

This paper outlines the position of the Alzheimer Society of Ireland with respect to the Assisted Decision Making (Capacity) Act 2015.

Some of the key points in this position paper include:

- This Act repeals the Marriage of Lunatics Act 1811 and cause the Lunacy Regulation (Ireland) Act 1871 to cease to have effect;
- The Act provides for the replacement of the Wards of Court system;
- The Act extends the remit of Enduring Power of Attorney (EPA) and all new EPAs will come under the provision of the Act;
- The Act legislates for Advance Healthcare Directives;
- The Act has key guiding principles, which must be complied with;
- The main guiding principles relate to the presumption of capacity, a functional approach to capacity and adherence to will and preferences rather than best interests;
- The Act sets out 3 decision support options, which includes assisted decision maker; co-decision maker and decision-making representative;
- The Decision Support Service will oversee the implementation of the Act and is the main structural support for registering decision making agreements; reviewing and monitoring agreements; developing codes of practice and rolling out education and training to ensure the Act is complied with in wider society;
- The Act will impact on other key pieces of legislation such as the Nursing Home Support Scheme (NHSS) but this has yet to be seen;
- The Act greatly enhances the human rights of people with dementia and is a welcome development to progress the autonomy, dignity and self-determination of people with dementia.

1. Introduction

The Assisted Decision-Making (Capacity) Act 2015 provides a modern statutory framework supporting decision-making by adults who have difficulty in making decisions unaided. It repeals the Marriage of Lunatics Act 1811 and cause the Lunacy Regulation (Ireland) Act 1871 to cease to have effect. The Act provides for the replacement of the Wards of Court system for adults, which is the existing mechanism for managing the affairs of persons whose capacity is impaired, with a range of legal options on a continuum of intervention levels to support people in maximising their decision-making capability. This legislation is a key step in enabling ratification of the UN Convention on the Rights of Persons with Disabilities.

It is important to note that well over half of decisions under the UK Mental Capacity legislation relate to people with dementia. In light of this and of the projected increase in numbers of people with dementia, it makes sense that the Irish legislation and any structures introduced under it are “dementia proofed” to ensure that they fully meet the needs of people with dementia as well as other groups likely to experience difficulties with capacity.

For this reason, the Alzheimer Society of Ireland played a significant advocacy role, since the Irish legislation on capacity was published in 2013, to ensure that the proposed legislation improves the situation of people with dementia. In doing so, ASI has drawn on a unique combination of dementia advocacy experience, knowledge of international best practice relating to dementia, and the collective experience of people who use our services and of staff and volunteers about the day-to-day issues facing people with dementia and their families. ASI has made a number of submissions to the Department of Justice and Equality as well as participating in a collaborative working group led by the Centre for Disability Law and Policy, NUI Galway (previously led by Amnesty International). ASI also made representations regarding Advance Healthcare Directives (AHDs), which are to be incorporated into the legislation, as well as leading out on a collaborative submission on AHDs with other ageing organisations.

The Alzheimer Society of Ireland welcomes this legislation as it sets out to safeguard the autonomy and dignity of the person with impaired capacity and believe that it will have a significant impact on realising the human rights of people with dementia.

The following position paper will give a general overview of the key dimensions of the legislation as well as highlighting the relevance of changes for people with dementia, carers and service providers including ASI. It concludes with a brief comment on what the legislation does not cover and a summary of how ASI intend to influence implementation of the legislation.

2. Overview of the Assisted Decision Making (Capacity) legislation

The starting point for introducing this legislation for the Irish Government was to meet Ireland's obligations under Article 12 of the Convention on the Rights of Persons with Disabilities. This is in line with the Government's commitment in the Programme for Government to introduce this legislation. Article 12 of the convention views equal recognition before the law as a fundamental right for people with disabilities, which includes people with dementia.

The Act is intended to address three broad categories of people. These are people with disabilities, particularly intellectual disabilities, older people with degenerative cognitive conditions and people with mental health issues who may have fluctuating capacity. The philosophy of the Act is to safeguard the person's autonomy to the greatest extent possible, stressing the importance of the person's 'will and preferences'.

2.1 Guiding principles of capacity legislation

Part 2 of the Act sets out nine guiding principles. These are intended to safeguard the autonomy and dignity of the person with impaired capacity. The most significant elements of these principles include:

- A presumption of capacity;
- Where capacity is in question, a functional or task approach to capacity must be taken;
- There is to be no intervention unless necessary in individual circumstance and any intervener must choose least restrictive alternative;
- Will and preferences and beliefs and values of the person must be central to all decision making.

2.2 Major changes from the legislation

Overall, three major changes to how we perceive and treat capacity arise from this legislation and specifically from the guiding principles. These include the presumption of capacity; the use of a functional approach to capacity; and the shift from 'best interests' to will and preferences. These are addressed in turn below.

Presumption of capacity

First, the **presumption of capacity** means that everyone, regardless of age appearance or diagnosis has capacity unless shown otherwise. When a person has an everyday decision to make the person assessing capacity in that instance is the person presenting the decision. Capacity is always assumed. The assessor will mainly be family or staff or other carers.

In more complex, contentious or very serious decisions (such as where to live) there will be a multifaceted approach to decision making capacity involving for example, carers and family members who know the person well, a social worker, a medical professional who can describe how the person's decision making ability is affected by the condition, the person themselves and/or an advocate representing their point of view.

Functional approach

This leads to the second major change this Act brings and that is moving Ireland from a "status-based" approach to capacity to a **"functional" approach**. This means that an individual with, for example, a dementia diagnosis, would no longer be presumed to lack capacity simply because he or she has a diagnosis. Instead, that individual would be presumed to have capacity and, if that capacity is called into question, capacity is to be determined in a decision-specific, time-specific fashion; i.e. for any given decision, capacity is to be decided based on the individuals understanding of that decision, at that time. Capacity is taken on a case-by-case basis and not connected to diagnosis. And while an individual may have reduced capacity for a certain decision today, he or she may well have capacity for other decisions today, and may regain capacity for all decisions in the future.

The functional test for capacity is NOT a medical test. In some complex cases medical input might be useful, alongside input from people who know the person well, to understand how the person's decision making is affected by their condition. There are four ingredients to this functional approach to capacity. A person has capacity if they **understand** the information relative to the decision and if they can **retain** it long enough for the purposes of making the decision and they can **weigh** it up and they understand the consequences. The final part is **communicating** a decision and doing this during the decision-making process. This is where diverse approaches to communication is critical and awareness of a person's will and preferences paramount.

The Alzheimer Society of Ireland has stressed the importance of a functional approach to capacity to ensure that a system of assisted decision making evolves which has the flexibility to allow people with dementia the time and support they need to understand, consider and communicate a decision. Examples of the most common practicable steps towards helping a person with dementia make a decision include:

- Establishing a time of day at which a person functions best and approaching them at that time.
- Establishing the environment in which the person functions best and approaching them in that environment.
- Establishing the people with whom the person communicates best and involving them in the communication process.
- Explaining written information orally, or writing oral information down in simple form to enable retention of information.
- Using “talking mats” or other communication aids developed for people with specific needs.
- Discussing the same issue on a number of different occasions to establish whether the person’s view remains consistent.

Will and preferences

The third major change is that this Act places strong emphasis on the **“will and preferences”** of the individual. The shift away from 'best interests' as the first point of call for decision making focuses decision making more on the guiding principles of autonomy, dignity, privacy and bodily integrity, which are basic human rights for all people, including older people. To date, decisions have been made for people, presumed to be lacking capacity, in their best interests regardless of whether a person or family member claims an alternative decision or had previously expressed an alternative preference to what is perceived as in their best interests. The legislation will place an onus on those requiring a decision to be made to ensure that a person is involved in that decision, capacity is assumed and a decision is based on a person’s values, wishes and will and preferences.

3. Key structures and elements of the legislation

The Assisted Decision Making legislation is generating a number of important changes. These include enhanced decision making options or relationships and supports for people; changes to wardship; changes to the Enduring Power of Attorney system; the introduction of a legal basis for advanced healthcare directives; and the establishment of the Decision Support Service.

These are explained in some more detail here:

3.1 Decision making options

The Act has 3 decision making options or relationships. These can be formed if the person (decision maker appointer) is seen to need support to make a given decision. They range in the level of involvement of others in supporting the decision-maker appointer as well as different mechanisms for operation of, and registration of, the decision making agreement. There are guidelines on how to manage decision making options. The Act will also see codes of practice being developed to guide the legislation in practice.

The assisted decision-making	**The co-decision-making**	**The decision making representative**
This option is aimed at a person whose decision-making capacity is somewhat impaired but who, with the necessary information and explanation, could exercise decision-making capacity. A person chooses an assistant to assist with decisions on personal welfare or property and affairs, or both.	This option relates to a person who has some decision-making capacity but who is unable to make decisions even with the help of a decision-making assistant. A system of co-decision-making will then be devised. A person chooses a co-decision maker to jointly make one or more decisions on personal welfare or property and affairs. A co-decision-making agreement must be registered with the Decision Support Service to have effect.	This option is for situations where a person is not able to take decisions even with the assistance of a decision making assistant or working with a co-decision maker. For people who are not able to make decisions even with assistance, the Act provides for the Circuit Court to appoint a Decision-Making Representative.

Table 1: Decision making options

3.2 Wardship

To date, when a person became unable to manage his or her assets because of mental incapacity, an application was made to the courts for this person to become a Ward of Court. Under the new legislation, there will be a review of all existing wards within a period of 3 years from operation of this legislation. If the person is found to have capacity then the ward will be discharged and property returned. If they are found to lack capacity they will be assessed as to what decision-making support is necessary from co-decision-making or decision-making representative.

3.3 Enduring Power of Attorney (EPA) and Advanced Healthcare Directives (AHD)

The Act will facilitate advance planning through two important provisions, namely enhancing the enduring powers of attorney system and introducing a legal basis for advance healthcare directives.

These options allow a person to plan for a situation of impaired capacity and to appoint someone that he or she trusts to take care of his or her affairs if that situation arises.

Enduring Power of Attorney (EPA)

A power of attorney is a legal device in Ireland that can be set up by a person during his/her life when he/she is in good mental health. It allows another specially appointed person (the attorney) to take actions on the donor's behalf if he/she is absent, abroad or incapacitated through illness. Existing powers of attorney that have been registered will continue to have effect. However, existing powers of attorney that have not been registered will come within provisions of the new legislation. Once legislation is enacted all new EPAs must be created under the Assisted Decision-Making (Capacity) Act. Notably, the principles set out in the capacity legislation will apply to attorneys and there will be an obligation to ascertain will and preferences and to take account of beliefs and values even when an EPA is registered.

Advanced Healthcare Directive (AHD)

An advance healthcare directive means an advance expression of will and preferences made by a person with capacity, concerning treatment decisions that may arise in the event that the person subsequently loses capacity. Any person has a legal right to consent to and to refuse medical treatment. An advanced healthcare directive will ensure that a person whose decision-making capacity is an issue still has the legal right to consent to and refuse medical treatment.

Under the legislation a person can designate a named individual (or alternate) to exercise the powers of a designated healthcare representative. If a representative agrees to exercise these powers then he/she must sign an AHD to confirm willingness to do so in accordance with will and preferences as determined by reference to the directive. The maker of an AHD may confer on his or her patient-designated healthcare representative (DHRep) the following:

- The power to advise and interpret what the directive-maker's will and preferences are regarding treatments as determined by the DHRep by reference to AHD; and
- The power to consent to or refuse treatment, up to and including refusal of life-sustaining treatment based on the known will and preferences of the directive-maker as determined by the DHRep by reference to AHD.

3.4 Decision Support Service (DSS)

The Assisted Decision-Making (Capacity) Act 2015 provides for the appointment of a Director together with support staff to form the Decision Support Service. This service will be part of the Mental Health Commission, an independent statutory body established in 2002. The Director will promote public awareness of the law, provide information and guidance, develop codes of practice, advise state bodies, make investigations and keep a record of assistance agreements and reports from representatives.

3.5 Codes of practice

The codes of practice developed will be important in terms of ensuring that the legislation can have a real impact for people on the ground.

The Director of the Decision Support Service will be responsible for publishing all codes of practice related to assisted decision making. The Minister for Health will appoint a multi-disciplinary Working Group to formulate an overarching code of practice for healthcare professionals. The remit of the Working Group will be to 'interpret' and expand in detail the legislation i.e. develop an overarching code of practice for healthcare professionals. There will be a need for more detailed profession-specific codes of practice. Such codes will most likely focus on day-to-day practice. While the Director of the Decision Support Service will be the person responsible for publishing all codes of practice, it is likely that professional bodies will need to develop profession-specific codes of practice.

4. Relevance of legislation to people with dementia and their carers

The most significant change that this legislation will bring to the lives of people with dementia and their carers is a legislative framework for decision making. Prior to this legislation, although family's support people with dementia in decision making, there has been no legal basis for this support. This new legislation places a legal onus on clinicians and other health professionals and service providers to include the designated assistant and co-decision makers in decision-making. However, the legislation gives additional decision making options and also allows for a legal basis for planning ahead for healthcare issues.

It is important to note that while dementia follows a predictable path in terms of continued deterioration of a person's ability to make decisions and carry out everyday tasks, in the early to mid-stages there may be considerable fluctuation in their ability. Time of day, familiar or unfamiliar setting, means of communication, physical health and other factors may all impact negatively or positively on the ability of a person with dementia to exercise capacity. This means that decision making legislation underpinned by will and preferences and a functional approach to capacity will inevitably enhance the human rights of people with dementia.

5. Relevance of legislation to ASI as a leading advocacy organisation and service provider

As a service provider, the legislation will impact on practice and policy for the Alzheimer Society of Ireland. These changes are in line with best practice in dementia care as they enhance autonomy, dignity and self-determination for people with dementia. Services will need to review:

- Training needs of staff and volunteers related to the new legislation;
- Documentation in terms of making more notes and references to values, wishes and will and preferences of service users;
- Practice in terms of how staff and volunteers use a functional approach to capacity and ensure the legislation is adhered to; and
- Paperwork, which should reflect good practice under the legislation. This applies to application forms, assessment forms and all other forms that should place the person with dementia central to decisions. Some key questions here include how is consent dealt with in practice and on paper? Is there a tick box to identify any of the various types of decision making arrangements which may be in place? Is there an easy –to-use form to assist capacity assessments? Are there plenty of spaces in day-to-day record keeping to take note of "will and preferences"?

As an advocacy organisation, the legislation will provide ASI with a tool to progress human rights for people with dementia. ASI can also play a lead advocacy role to ensure that the legislation impacts positively on the ground for people living with dementia.

6. What the legislation does not cover

The ASI is aware that the legislation does not address deprivation of liberty issues. This issue will be addressed in further legislation in 2016. That proposed legislation will need to address liberty issues for people who are not free to leave the institution in which they are cared for but who are incapable of consenting to such care: the "incapacitated but compliant" patient whose situation was considered by the European Court of Human Rights in H.L. v. United Kingdom HRC MRLR (2005) 40 EHRR 761 [2004] 1 MHLR 236 ("the Bournewood case").

The Irish courts have interpreted the Mental Health Act 2001 as allowing the detention of compliant incapacitated patients in approved centres (EH v St Vincent's Hospital and Ors[2009] IESC 46). The courts have not yet specifically considered the situation of a resident in a nursing home who is not free to leave but cannot consent to remain. The Irish Human Rights Commission has expressed concerns that the decision in EH case leaves Ireland exposed to an action for breach of the ECHR1 . The European Committee on Prevention of Torture in its recent report on Ireland expressed concerns over its observations in a number of institutions where people were effectively detained without any safeguards against unlawful deprivation of liberty being in place.

A second gap in the capacity legislation is the lack of a statutory right to advocacy, which could have played a significant role to ensure that people with dementia can exercise their new rights under the legislation. People with dementia, due to a combination of the symptoms of the dementia and the stigma surrounding it, are at a very real disadvantage when it comes to expressing their needs and wishes and asserting their rights. Independent advocates could have played a valuable role in this regard.

A final concern is the interface with other legislation such as the Nursing Home Support Scheme (Fair Deal) legislation, which has not been clarified in the capacity legislation. Will it remain appropriate to use a Care Representative to consent to the financial arrangements of the scheme in the case where the individual lacks capacity? This might mean two parallel systems for determining capacity in relation to financial affairs and two systems of appointing a representative.

7. Conclusion: Implementation of capacity legislation

The Alzheimer Society of Ireland welcomes this legislation as it supports the human rights of people with dementia. People with dementia and their carers now have a legislative basis for decision making when capacity is an issue. The new functional approach to capacity means that capacity always relates to a particular decision at a particular time**.** The focus is on a person's values, wishes and will and preferences. The guiding principles of the legislation and the new Decision Support Service will have a significant impact on policy and practice in Ireland and further support people with dementia and their carers to live well with dementia.

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