

## **Assisted Decision-Making (Capacity) Act 2015 Guide for Health and Social Care Professionals Consultation**

**April 2017**

### **Introduction**

Care Alliance Ireland welcomes the publication of the Guide for Health and Social Care Professionals regarding the Assisted Decision-Making (Capacity) Act 2015. Family Carers provide upwards of €4billion worth of care every year, and this Act will have a significant impact on the lives of many of Ireland's 360,000 Family Carers, and it vital that health and social care professionals are well-informed as to the reach of that impact, and how best to work with Family Carers to ensure the Act works as well as possible.

### **About Care Alliance Ireland**

There are approximately 360,000 Family Carers in the Republic of Ireland<sup>1</sup>. Family Carer support is provided by a number of organisations, including those dedicated solely to carer support and others who support carers as part of their response to individuals with specific conditions.

Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. Our vision is that the role of Family Carers is fully recognised and valued by society in Ireland. We exist to enhance the quality of life of Family Carers. We achieve this by supporting our 80+ member organisations in their direct work with Family Carers through the provision of information, developing research and policy, sharing resources, and instigating opportunities for collaboration.

Our legitimacy derives from our membership base which includes all the carer organisations and virtually all of the disease/disability-specific organisations currently providing services to Ireland's Family Carers. Our membership comprises organisations both large and small, and both regional and national.

We work with organisations in order that they can enhance the information and supports they provide to Family Carers. We provide them with opportunities to collaborate on initiatives including National Carers Week, a multi-agency and multi-disciplinary Family Carer Research Group, and joint policy submissions. We actively encourage collaboration in all our projects. We provide cohesion to those

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<sup>1</sup> Central Statistics Office, "CSO Releases Irish Health Survey Results," November 16, 2016, <http://cso.ie/en/media/csoie/newsevents/documents/pressreleases/IHS2015.pdf>.

organisations working to support Family Carers. We commission relevant research that supports quality interventions in the lives of Family Carers.

By focusing on these functions we enable more of our member's resources to go directly to coal face services.

***This document is an adapted version of the submission made by Care Alliance via the provided online form in April 2017. As such, the sections of this submission were delineated by the particular questions asked of those making submissions.***

### **Ease of reading**

While in general, the guide is relatively easy to understand, there are a number of terms and concepts which do need some level of clarification, details below.

#### **Page 6:**

*"Enduring Power of Attorney (EPA)*

*An EPA is an arrangement whereby a Donor (the person who has capacity) gives authority to an Attorney (the person to whom authority is given) to act on their behalf in the event that the donor lacks decision-making capacity at any time in the future."*

The term "donor" in this instance needs to be fully explained. It does not have an entry in the glossary, which could cause confusion as the guidance also speaks of organ donation, etc.

#### **Page 18:**

*"The 2015 Act also provides that any person appointed to assist or support a relevant person to make a decision must be a suitable person to be appointed. There must be no conflict of interest in relation to his or her own interests and the interests of the relevant person."*

What constitutes a "conflict of interest" needs to be clarified within the document.

#### **Page 33:**

*"Section 8 (10) – the intervener, in making the intervention in respect for a relevant person...*

*(c) shall take reasonable steps to ensure the relevant information:*

*(i) is kept secure from authorised access, use or disclosure, and is safely disposed of when he or she believes it is no longer required."*

Should this read "unauthorised access", rather than "authorised access"? Currently it needs clarification.

## **Gaps in information in the Guide**

### Impact upon Family Carers

Whilst we appreciate that this guide is designed to educate professionals in the health and social care field, we feel it is vital to include some discussion of how this Act, and its implementation, will affect the lives of Family Carers, and how health and social care professionals will need to work with families as part of the implementation of this legislation.

Many of Irelands 300,000+ Family Carers provide care and support to individuals who will come under the bounds of this legislation. By necessity, it will be vital to include families in discussions regarding the capacity of any individual person whom they provide care for.

We note the inclusion of Family Carers within point 2.7 (page 32), however this brief mention is not sufficient given the responsibilities held by Family Carers and their investment in the correct care and positive outcomes for the person they care for. In addition, the point made in this section ("The 2015 Act requires that certain people must be consulted when an intervention is being made, unless it is not appropriate and or practicable to do so (see 2.6.2).") may clash with the National Carers Strategy (see point below).

### Who is a Co-Decision Maker?

It is not clear within the guidance whom can act as a Co-Decision Maker, who can be appointed as a Decision Making representative, and what exactly the boundaries of their roles are. Can family members occupy these roles? Strong definitions and explanations of these terms need to be included in the document. We acknowledge that they are included in the glossary, however this short definition is not sufficient.

### Who may challenge a persons capacity?

Section 4.2.1 (page 44) includes the following statement;

*"If a health and social care professional is considering challenging a person's capacity to make a decision, the onus is on that professional to show that an adequate trigger exists to challenge the presumption of capacity (which includes going through the steps in the process without success – see 3.2)."*

Whilst perhaps outside the scope of this document, it is important to note whether a family member can also challenge a persons capacity. Information for professionals who may need to support the family as a whole through this process- which is potentially a challenging scenario and one which has the possibility to negatively impact on family relationships- is missing from these guidelines. It is almost as if there is an assumption that families and Family Carers will be excluded from the entire process. Many of the member organisations that make up Care Alliance Ireland have a role in supporting both the cared-for person, and the Family Carer.

### Contradictions with the National Carers Strategy

Whilst it is outside of the scope of this document, given that the legislation cannot be changed, it is important to note that the Act appears to have the potential to contradict some of the core principles of the National Carers Strategy (2012). In particular, Strategic Goal 1: Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for. We understand that legislation overrides written policy which does not have a legislative basis, however the impacts of this will be felt by professionals supporting families and Family Carers, who have primary responsibility for the health and wellbeing for their loved ones.

### Supports needed for professionals

A significant training and education schedule for professionals in statutory and voluntary organisations will be vital to ensure successful roll out and compliance with this legislation. Bringing families together with professionals would be an innovative way of combatting the inevitable but manageable conflict which will arise as the legislation is implemented. Communication between all parties who will be impacted by this legislation must be open and respectful, whilst being mindful of the legal imperatives that now exist within the sector. This will be particularly relevant for professionals working with individuals with significant cognitive and communication difficulties, whom family members are used to speaking on behalf of. This legislations is indicative of a significant culture and paradigm shift for those families.