

Assisted Decision-making (Capacity) Act 2015

Relevant person- a recalibration for the centrality of rights or just more semantics?

Family Carers Ireland is a national charity that works to improve supports and recognition for families and friends caring for someone who is ill, frail, disabled or has a mental health difficulty. The CSO estimated that there were 355,000 carers in Ireland in 2015¹, providing an average of almost 45 hours of unpaid care a week, many in addition to holding down a full- or part-time job. A significant minority of these people will be directly affected by the provisions of the Assisted Decision-making (Capacity) Act 2015, not least of which as they will be the most likely person to assume the role of an Assistant Decision Maker, a Co-decision Maker, a Decision Making Representative or a Designated Healthcare Representative in the case of Advanced Healthcare Directives. *Family Carers Ireland* believe that the Act will bring significant and lasting benefits to family carers and those for whom they care and in particular welcome;

- the replacement of the long out-dated Lunacy Regulation (Ireland) Act of 1871;
- the creation of a continuum of decision-making aids, ranging from informal support to more extensive decision-making arrangements;
- the move from an all or nothing status approach to a flexible 'functional' view of capacity assessed on an issue-and-time specific basis;
- the abolition of the Wards of Court system, the review of capacity of all existing wards and the establishment of the Office of Public Guardian;
- the modernisation of the law on Enduring Powers of Attorney.

Noting the title of session one 'Relevant Person –a recalibration of the centrality of rights or just more semantics?' it is our view that if we are serious about respecting the right of everyone to make choices for themselves, then we must recognise the practical measures that are needed to successfully implement the provisions of the Capacity Act, including training and support for family members, support for advocacy organisations, increased resources for health and social care professionals and the Courts system as well as interim measures to support the transition of the Act towards full commencement.

Notwithstanding the many positive reforms the Capacity Act will bring, *Family Carers Ireland* are concerned with a number of aspects of the legislation, not least of which is **the very considerable responsibility placed on the shoulders of intervenors (often family members and carers) without adequate regard to supporting their needs or addressing any challenges they may encounter during the term of their decision-making intervention.** In fact, it has been made clear that the Capacity Act has a singular focus on the 'relevant person' and as such *Family Carers Ireland* are concerned that ancillary supports critical to the successful implementation of the Act, including supports for decision makers and families, are not being given the attention, consideration or resources they warrant.

A second concern is the **failure to provide transitional arrangements following the signing into law of the Act in December 2015 and the full commencement of the Act.** This failure has caused 'relevant' persons and their families to fall into a legal quagmire whereby the protections legislated for under the Act (i.e. decision making arrangements) are not yet available leading to carers having no legal status in terms of decision making in the interim. As a result, there has been an increase in Wardship applications as people seek legal clarity and which has created a situation entirely at odds with the principles of the Act.

¹ Irish Health Survey 2015.

Family Carers Ireland are concerned about the lack of clarity as to how the new system will be resourced. For example the Act outlines determination of capacity as a function of the Circuit Court. There is, however, insufficient detail about how the Circuit Court will make this determination or what procedures will be in place. While the intention of the Act is to assist people to make their own decisions in so far as possible, there will inevitably be situations in which capacity will need to be assessed by an independent assessor or panel of experts. Section 50 provides that in making such a declaration the Circuit Court “shall have all such powers as are necessary to assist it” including directing the preparation of expert reports. *Family Carers Ireland* has a number of concerns about how this will work in practice, particularly given current waiting times for access to the Circuit Court (in some cases up to one year) and the very significant challenges in accessing expert health professionals. We note for example, the difficulties experienced by persons trying to secure specialist medical reports required in their application for social welfare supports and the reluctance of some medical specialists to engage in the process. There are also significant costs involved in securing medical reports, with the financial burden often falling to families or carers. Finally, we also question whether an independent assessor or an expert panel’s ability to appropriately assess an individual’s capacity based on a desk review of medical reports and strongly recommend that all assessments of capacity are carried out in person with the individual present.

Finally, the Act requires court appointed decision-makers to submit an annual report to the DDSS on the performance of his or her functions with the format of such annual reports to be determined by the court. The Act also stipulates that the court, on appointing a decision-maker may require them to give security as it considers appropriate in relation to the proper performance of their functions. *Family Carers Ireland* is concerned with the lack of detail provided with regard to such annual reports, the level and type of information required and the **additional burden this places on decision-makers who will already be fulfilling the incredibly arduous task of acting on behalf of the individual concerned, without payment.** By comparison, ‘professional’ decision makers appointed by the court when no appropriate intervenor is available, will be paid for their efforts.

Other possible questions:

- What costs will be involved in going to the Circuit Court to appoint for a Decision-making Representative and who bears responsibility for these costs, the relevant person or intervenor?
- The Act stipulates that a Decision-making Representative shall, at least once every 12 months prepare and submit to the DDSS a report as to the performance of his or her functions. What level of information will be required in these reports, will templates be available and what sanctions, if any, will Decision-making Representatives face if they fail to submit a report or to provide adequate information?
- The Act outlines determination of capacity as a function of the Circuit Court. How will the Court make such a determination?
- Who is responsible for meeting the costs medical reports?
- Where and how should Advance Healthcare Directives be recorded to ensure swift access in emergency situations i.e. when a person presents at A&E following an accident.