

IRELAND: ASSISTED DECISION-MAKING (CAPACITY) ACT 2015 AND ARTICLE 12 OF THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

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Abstract: in 2015, Ireland enacted reforming legislation to provide for adults who require assistance to exercise their decision-making capacity. At time of writing, the Assisted Decision-Making (Capacity) Act 2015 ('the 2015 Act') is largely not yet operational and practical work to prepare for its commencement is ongoing. In March 2018, Ireland ratified the United Nations Convention on the Rights of Persons with Disabilities ('CRPD'). Article 12.2 of the CRPD states that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. At ratification, Ireland entered a declaration and reservation in respect of Article 12 to permit the retention of a form of substitute decision-making. This article reviews the key reforms introduced in Ireland under the 2015 Act, the competing perspectives on states' obligations under Article 12 and the extent to which the 2015 Act may be said to achieve compliance.

Keywords: capacity; decision-making capacity; human rights; mental capacity; substitute decision-making.

INTRODUCTION

On 30 December 2015, the President of Ireland signed into law the Assisted Decision-Making (Capacity) Act. According to its long title it is:

"An Act to provide for the reform of the law relating to persons who require or may require assistance in exercising their decision-making capacity, whether immediately or in the future..."

The signing of the 2015 Act came about after extensive consultation and a protracted legislative process and it has been broadly, if not unreservedly, welcomed as reforming, rights-based legislation. A national association for people with an intellectual disability has described it as a 'seismic cultural shift towards a rights-based approach of choice, control and consent'¹. Although fully enacted, the 2015 Act is largely not yet operational. Statutory instruments have been passed to commence certain sections providing for preparatory

¹ Inclusion Ireland, *Assisted Decision-Making (Capacity)*, www.inclusionireland.ie (accessed February 2020).

matters, including the appointment of the Director of a new Decision Support Service². Practical work is ongoing to prepare for the commencement of the substantive sections of the Act.

The main reforms introduced under the Act include:

- * a statutory definition of capacity based on a functional assessment;
- * a regulated three-tier framework for decision-making;
- * detailed guiding principles rather than a ‘best interests’ standard;
- * enhanced tools for advance planning by way of enduring powers of attorney and advance healthcare directives;
- * the establishment of the Decision Support Service with numerous functions to promote and regulate the new framework.

The Act applies only to persons over the age of 18. The Department of Justice and Equality, has estimated that over 200,000 adults in Ireland may have decision-making capacity difficulties, which *could* (emphasis added) bring them within the parameters of the Act³. This is based on numbers of persons with intellectual disabilities, acquired brain injury, mental illness and age-related degenerative disorders. It is important to note that all of these adults, whatever their presentation, are presumed capable of making their own decisions independently and, as discussed below, the Act does not adopt any medical or other diagnostic criteria for assessing decision-making capacity.

Ireland ratified the United Nations Convention on the Rights of Persons with Disabilities in March 2018, having been an early signatory in 2007. Ireland operates a dualist system; under Article 29.6 of the Constitution⁴, international agreements have force of law to the extent determined by the Irish parliament. The government has identified full commencement of the 2015 Act as essential to compliance with multiple articles of the CRPD⁵.

EXISTING STRUCTURES PRE-2015 ACT

Pending commencement of the 2015 Act, there are only two formal legal mechanisms in Ireland to provide for adults who lack decision-making capacity.

Since 1996, it has been possible for an adult to plan ahead by making an enduring power of attorney. This allows the donor of the power to appoint a trusted person, usually a family member, to act as his or her attorney in the event that the donor becomes ‘mentally incapable’ of taking these decisions

² The writer of this article commenced in post as Director in October 2017.

³ Department of Justice and Equality, *Assisted Decision-Making (Capacity) Bill Regulatory Impact Analysis*, 13 June 2013.

⁴ Art 29.6 *Bunreacht na hÉireann* 1937.

⁵ Department of Justice and Equality, *Roadmap to Ratification of the United Nations Convention on the Rights of Persons with Disabilities*, October 2015.

independently⁶. The power may be general or specific in nature and authorises the attorney to take decisions on the donor's behalf in relation to the donor's financial affairs or personal care.

The only other legal mechanism is the court-based system of wardship, a form of plenary guardianship. Wardship, whereby the court is vested with jurisdiction over all matters relating to the person and estate of the ward has its origins in the *parens patriae* doctrine and the exercise of the royal prerogative. The primary procedural legislation dealing with wardship is the Lunacy Regulation (Ireland) Act of 1871 ('the 1871 Act'). After Independence, jurisdiction transferred ultimately to the President of the High Court⁷.

When admitting a person to wardship, the court declares the person to be, 'of unsound mind and incapable of managing his person or property'⁸.

In a 1996 decision, the Supreme Court confirmed the status of the ward as a holder of rights. The Chief Justice stated:

*"The loss by an individual of his or her mental capacity does not result in any diminution of his or her personal rights, recognised by the Constitution, including the right to life, the right to bodily integrity, the right to privacy, including self-determination and the right to refuse medical care and treatment"*⁹.

The ward, although a holder of rights, is evidently dependent on the court for the exercise of these rights. The Supreme Court held that the paramount consideration must be the best interests of the ward and approved the finding that the proper approach was 'the standpoint of a prudent, good and loving parent'¹⁰.

The arguments against plenary guardianship are well rehearsed. It is often described in the literature as 'civil death'. The effect of being declared 'of unsound mind' is that, irrespective of the specific purpose or context of the wardship application, the ward is deprived of decision-making autonomy in unrelated and even quite minor matters. The Supreme Court has recently acknowledged this 'over-broad' and 'disproportionate' impact of wardship, stating:

*"An order making a person a ward of court has real consequences. It can deprive a person of the power to make many of the choices which are fundamental and integral to day-to-day life"*¹¹.

A further criticism of wardship concerns the extent to which the ward has access to the court process and to representation. In a 2017 review of current

⁶ Powers of Attorney Act 1996.

⁷ Section 9(1) Courts Supplemental Provision Act 1961.

⁸ Order 67 Rule 1 Rules of the Superior Court.

⁹ *In the Matter of a Ward of Court (Withholding Medical Treatment) (No.2)* [1996] 2 IR 79 p. 128.

¹⁰ *Ibid.* p. 127.

¹¹ *HSE v. A.M. McMenemy J.*, Supreme Court 29 January 2019 para. 8.

wardship practice, the National Safeguarding Committee found significant deficiencies in current procedures¹². In October 2019, the Supreme Court expressed concern about the lack of fundamental safeguards, stating that one of the most salient aspects of the process was the absence of the ward's voice¹³.

It is understood that there are at present approximately 2150 adult wards of court and that numbers have recently risen year on year¹⁴. People with age-related degenerative illness comprise the largest single category people taken into wardship¹⁵. In approximately 600 current cases, the General Solicitor for Wards of Court and Minors, a public official, has been appointed to act as the 'committee' for the ward, in the absence of any suitable family member. The committee takes day-to-day decisions under the supervision of the court, while the court reserves to itself decisions in more serious matters.

It appears that in recent years, an increasing number of applications for wardship are increasingly based on safeguarding concerns or the need to secure consent for health and social care interventions, rather than the preservation of assets. Often these applications are brought by the Health Service Executive, the national provider of health and social care services.

The 2015 Act repeals the Lunacy Regulation (Ireland) Act of 1871. All current wards will have their cases reviewed within three years of commencement of the 2015 Act at the latest¹⁶ and may transition to the new statutory framework. An even older statute, the Marriage of Lunatics Act 1811, which prohibits wards of court from getting married is also repealed¹⁷. There are no other relevant statutes to repeal. It must be surmised, given that only a small fraction of the population¹⁸ are wards of court or have registered enduring powers of attorney¹⁹ that every day, decisions are made informally on behalf of adults with decision-making capacity difficulties on the basis of policy, custom and practice.

The idea persists that the next-of-kin enjoys some legal status as a substitute decision-maker. In relation to adults, 'next-of-kin' has meaning only in succession law. A survey conducted in January 2018 found that 57% of respondents believed that their next-of-kin could make healthcare decisions or consent to treatment on their behalf and 32% believed their next-of-kin could access their bank accounts and assets²⁰. As discussed below, the 2015 Act

¹² National Safeguarding Committee, *Review of current practice in the use of wardship in Ireland* (2017).

¹³ *A.C. and Others v. Cork University Hospital* [2019] IESC 73 para 366.

¹⁴ Dáil Éireann Debate, *Wards of Court* 20 November 2019.

¹⁵ Data supplied by the Office of the Ward of Court.

¹⁶ Section 54 2015.

¹⁷ Section 7 2015.

¹⁸ Ireland's total population is close to 5 million people.

¹⁹ *Courts Service Annual Report (2018)*, p. 76: 985 Enduring Powers of Attorney were registered in 2018.

²⁰ Sage Advocacy, *Next of Kin Survey*, January 2018.

does not recognise informal substitute decision-making arrangements, in either property and affairs or personal welfare matters, minor or otherwise.

REFORMS UNDER THE 2015 ACT

Following two papers by the Law Reform Commission²¹ a Mental Capacity Bill was first published in 2008. This led to further debate and engagement with the legislature by an influential coalition of civil society groups, using arguments based on Article 12 of the CRPD²². This group was successful in arguing for significant amendments, including a change of name to the Assisted Decision-Making (Capacity) Bill, which was published in 2013. The term 'mental capacity' does not appear at all in the final 2015 Act.

KEY REFORMING FEATURES OF THE 2015 ACT

A person's capacity is to be construed functionally.

'Capacity' has a singular meaning in the 2015 Act. It refers only to decision-making capacity. Section 3 of the Act states that,

*"(...) a person's capacity shall be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at that time"*²³.

As mentioned, there is no diagnostic threshold in the 2015 Act. In this respect, the 2015 Act differs from the Mental Capacity Act in England and Wales which defines incapacity as deriving from 'an impairment of, or a disturbance in the functioning of, the mind or brain'²⁴. There are some arguments that the inclusion of a diagnostic criteria can operate as a safeguard to prevent 'net-widening'. Clough writes that the impairment requirement in the Mental Capacity Act was recommended by the Law Commission to avoid 'paternalistic interventions into the lives of those who were merely eccentric'²⁵. The preferred approach of the Law Reform Commission in Ireland was to adopt a definition of incapacity which was based on a person's abilities and, as such,

²¹ Law Reform Commission, *Consultation Paper on Law and the Elderly* (LRC CP 23-2003); *Report on Vulnerable Adults and the Law* (LRC 83-2006).

²² O'MAHONY, Charles, "The Impact of International Human Rights Law on Irish Mental Health and Mental Capacity Law Reform", *Medico-Legal Journal of Ireland*, Vol. 23, No 1, 2017, p. 24.

²³ Section 3(1) 2015.

²⁴ Section 2, Mental Capacity Act 2005.

²⁵ CLOUGH, B., "New Legal Landscapes: (Re)constructing the Boundaries of Mental Capacity Law", *Medical Law Review*, Vol. 26, No.2, 2018, p. 270.

intended to be disability-neutral²⁶. The absence of any diagnostic criteria means that assessment of capacity no longer requires medical expertise. Apart from certain sections dealing with specific reports, the Act is not exhaustive or prescriptive as to who may assess capacity.

The 2015 Act states that a person lacks capacity to make a decision if he or she is unable to understand information relevant to the decision; retain that information long enough to make a voluntary choice; to use or weigh up that information long enough to make a voluntary choice or to communicate his or her decision (whether by talking, writing, using, using sign language, assistive technology or any other means)²⁷.

The above test for capacity has already been articulated in common law in Ireland. In 2008, Ms. Justice Laffoy adopted a functional test in the High Court in *Fitzpatrick v. K*²⁸. In that case, the patient Ms. K. had objected to receiving an emergency blood transfusion following a post-partum haemorrhage. Ms. Justice Laffoy found that Ms. K. lacked capacity to refuse treatment. The evidence was that Ms. K. had told her doctors that she could be treated instead with Coca-Cola and tomatoes. The test was subsequently applied with the opposite outcome in *Governor of X. Prison v. PMcD*²⁹. The court found that Mr McD. understood all relevant information and the consequences of his decision to pursue a hunger strike in prison and to refuse medical intervention. Ms. Justice Baker ruled that the State was to respect his personal autonomy and give effect to his freely expressed decision³⁰.

The 2015 Act places important emphasis on *supporting* independent decision-making *before* any consideration is given to assessing capacity or moving to the formal supported decision-making. Section 3(3) requires that a person is not to be regarded as unable to understand information if he or she is able to understand an explanation of it in a way appropriate to his or her circumstances. The guiding principles, which we shall turn to next, state that a person 'shall not be considered as unable to make a decision unless all practicable steps have been taken, without success, to help him or her to do so'³¹. This writer is aware of discussion about what should 'trigger' an assessment of capacity under the 2015 Act. It is proposed that the focus instead should be on exhausting all other means to enable a person to arrive at an independent decision. The title of the Act, with 'capacity' in parentheses is reflective of this priority.

The functional assessment is considered further below in the context of compliance with Article 12 of the CRPD.

²⁶ Supra note 21 LRC CP 23 -2003 para 2.43.

²⁷ Section 3(2) 2015.

²⁸ [2008] IEHC 104.

²⁹ [2015] IEHC 259.

³⁰ Ibid. para 130.

³¹ Section 8(3) 2015.

GUIDING PRINCIPLES

The 2015 Act makes no reference at all to the term ‘best interests’, the standard which applies in wardship and in a number of other pieces of legislation, including the Mental Health Act³². Instead, an ‘intervener’³³ is obliged to give effect to a lengthy list of guiding principles in their interventions with a relevant person.

A person is presumed to have capacity in respect of a particular matter unless the contrary is shown as provided for by the Act³⁴. This principle already exists at common law³⁵.

A person shall not be considered unable to make a decision merely because the decision is unwise³⁶. This is sometimes misleadingly shortened to ‘the right to be unwise’. More accurately it is a rejection of the ‘outcome approach’, which would state that if what you want to do is unwise or contrary to prudent advice, then you must lack the capacity to decide to do it. A risky decision, particularly if it is out of character may raise legitimate concerns but, as the Law Reform Commission observed, such a decision may be indicative of a lack of understanding but should not be determinative of incapacity³⁷.

The guiding principles emphasise minimal restriction on rights and freedoms and due regard to the right of the relevant person to dignity, bodily integrity, privacy and control over his or her affairs³⁸. The intervener must encourage and facilitate as far as possible the participation of the relevant person in the intervention³⁹ and all interventions should be proportionate and limited in duration⁴⁰.

The guiding principles are not arranged in order of priority. Arguably however, the stand-out principle, from the point of view of alignment with the CRPD, is the requirement that an intervener must ‘give effect as far as is practicable to the past and present will and preferences of the relevant person, in so far as these are reasonably ascertainable’⁴¹. The intervener must take into account the beliefs and values of the person and any other factors which he or she person would be likely to consider and consult with other persons who have been nominated by the relevant person. The primacy of will and preferences is considered below in the context of Article 12 CRPD.

³² Section 4 Mental Health Act 2001.

³³ Section 2 defines ‘intervener’ to mean the courts, a decision-making assistant, co-decision-maker, decision-making representative, attorney or designated healthcare representative, a special or general visitor or healthcare professional carrying out an action, making an order or giving a direction under the Act.

³⁴ Section 8(2) 2015.

³⁵ *Fitzpatrick v. K.*, supra note 28 at p. 40.

³⁶ Section 8 (4) 2015.

³⁷ Supra note 21 LRC 83-2006 para 2.26.

³⁸ Section 8(6)(b).

³⁹ Section 8(7)(a).

⁴⁰ Section 8(6)(d).

⁴¹ Section 8(7)(b).

The intervener must also ‘act at all times in good faith and for the benefit of the relevant person’⁴². ‘Benefit’ is not defined. Davidson writes that ‘benefit’, in the sense of contributing to the person’s well-being, encourages an intervener to be conscious of the effects of the intervention on the person⁴³. Donnelly has written that, as a shorthand expression of the importance of placing the person at the centre of the intervention, ‘benefit’ is somewhat unsatisfactory⁴⁴. It must mean and be seen to mean something other than best interests. It is notable that the Mental Capacity Act in England and Wales, includes a requirement to consider the person’s wishes and feelings *as part of* a determination of their best interests⁴⁵. However, it is apparent that the words ‘best interests’ have become freighted with negative connotations, perceived as a paternalistic, antithetical to individual rights, vague and subjective and primarily reflective of the values of the person applying the standard⁴⁶. As we shall see, the ‘best interests’ standard has been emphatically rejected by the UN Committee for the CRPD.

THE THREE-TIER FRAMEWORK

Under the 2015 Act, ‘decisions’ are divided into two categories: ‘personal welfare’, including healthcare, and ‘property and affairs’ decisions. The two categories are broadly defined⁴⁷. The 2015 Act introduces a graduated three-tier framework. It is possible that in respect of different decisions, a person could find himself or herself on different tiers at different times or not on the framework at all. The Act provides two forms of decision support and one of substitute decision-making as a last resort. The main features of each will be considered in turn.

DECISION-MAKING ASSISTANCE AGREEMENT (DMAA)

This is the lowest and least formal tier of support. A person who considers that his or her capacity is in question or may be called into question may appoint another person to act as his or her decision-making assistant (DMA) in respect of decisions relating to property and affairs or personal welfare or

⁴² Section 8(7)(e).

⁴³ DAVIDSON, H., “The Assisted Decision-Making (Capacity) Act 2015: How will it Change Healthcare for People with Dementia?”, *Medico-Legal Journal of Ireland*, Vol. 23, No 2, 2017, p. 62.

⁴⁴ DONNELLY, M., *Best Interests in the Mental Capacity Act: Time to Say Goodbye?* *Medical Law Review*, Vol. 24 No. 3, 2016, p. 331.

⁴⁵ Section 4(6), Mental Capacity Act 2005.

⁴⁶ Victorian Law Reform Commission, *Guardianship: Final Report (2102)* para 6.94.

⁴⁷ Section 2 2015.

both⁴⁸. The functions of the DMA are to assist the person to obtain information, to assist by explaining this information, to help the appointer make and communicate a decision and to endeavour to ensure that the decision is implemented⁴⁹. The decision remains that of the appointer alone.

This is probably the sort of assistance routinely provided informally within families⁵⁰. A limitation of such informal arrangements, however, is that third parties may query the role of the supporter and their entitlement to access and share information. This may well become more likely with a growing awareness of privacy and data protection obligations. A DMAA allows a person to set out the matters in which the DMA can legitimately provide this level of assistance.

The arrangement has been compared to 'representation agreements' in British Columbia⁵¹. However, there has been some criticism of DMAAs compared to representation agreements on the basis that the appointer must satisfy a capacity assessment⁵². In fact, there is no requirement in the 2015 Act for a capacity assessment in respect of DMAAs.

CO-DECISION-MAKING AGREEMENT (CDMA)

The middle tier of support provides for joint decision-making. A person who believes that his capacity is or may be called into question may appoint a trusted relative or friend to act as co-decision-maker (CDM) in respect of specified matters⁵³.

Compared to the DMAA, there are many more procedural requirements in respect of CDMA's. CDMA's must be submitted for registration with the Decision Support Service and are not valid unless registered. There are notice requirements to help safeguard against undue influence and to ensure that the co-decision-maker is suitable to act⁵⁴. Notice parties may object to registration on a number of grounds, including an objection that the proposed CDMA is not in accordance with the will and preference of the appointer⁵⁵. An application to register a CDMA must be supported by two statements, one from a medical practitioner and the other from another healthcare professional stating

⁴⁸ Section 10(1) 2015.

⁴⁹ Section 14(1) 2015.

⁵⁰ See KERZNER, Lana; "Supported Decision-Making Innovations: The Canadian Experience", O'MAHONY, Charles; QUINN, Gerard (eds.), *Disability Law and Policy: An Analysis of the U.N. Convention*, Dublin: Clarus Press, 2017, Chapter 9, p. 118.

⁵¹ Representation Agreement Act R.S.B.C 1996.

⁵² GOODING, Piers, *A New Era for Mental Health Law and Policy: Supported Decision-Making and the UN Convention on the Rights of Persons with Disabilities*, Cambridge: Cambridge University Press, 2017, p. 165.

⁵³ Section 17(2) 2015.

⁵⁴ Section 21(3) 2015.

⁵⁵ Section 24(1)(e) 2015.

that, in their opinion, the person has capacity to enter into the CDMA, requires assistance in relation to the decisions contained in the CDMA and has capacity to make the relevant decisions with the support of the CDM⁵⁶.

This is one of the two instances in the 2015 Act where capacity must be assessed by certain qualified professionals. What is new is the adoption of a multi-disciplinary approach. 'Healthcare professional' is broadly defined to include health and social care professionals. Whereas formal assessments of capacity are usually carried out by psychiatrists at present, the Act recognises the perspective of other professionals, who may have a more rounded view of the appointer and his or her living situation.

Once the CDMA is registered, the decisions referred to in the CDMA must be taken jointly⁵⁷. The register to be maintained by the Director of the Decision Support Service must be available for third parties to inspect where they can demonstrate a legitimate interest⁵⁸. It is expected that such parties will include financial and legal service providers and healthcare professionals who need to confirm the authenticity of a CDMA for the purposes of contracts and consent.

All CDMA's will be subject to annual review by the Director to ensure compliance by the CDM and that the capacity assessment remains valid⁵⁹. The CDM is obliged to submit annual reports detailing the performance of his or her functions⁶⁰. Subject to certain procedural matters, it is open to the parties to agree to vary and to revoke a CDMA⁶¹.

In the performance of their functions, CDMs must help to obtain, advise and explain information, ascertain the will and preferences of the person and assist the person with communicating his or her will and preferences⁶². The co-decision-maker is obliged to acquiesce with the wishes of the person, unless it is reasonably foreseeable that such acquiescence will result in serious harm to the appointer or to another person⁶³.

DECISION-MAKING ORDER/ DECISION-MAKING REPRESENTATION ORDER (DMRO)

At the upper tier, there is provision for substitute decision-making by order of the court, subject to safeguards and as a last resort. Under Part 5 of the Act, any person with a bona fide interest in the welfare of a relevant person may make an application to the court for a declaration in relation to a person's

⁵⁶ Section 21(4)(f) 2015.

⁵⁷ Section 23(2) 2015.

⁵⁸ Section 25(3) 2015.

⁵⁹ Section 26 2015.

⁶⁰ Section 27 2015.

⁶¹ Sections 28 and 29 2015.

⁶² Section 19(1)(b) 2015.

⁶³ Section 19(5) 2015.

capacity⁶⁴. The applicant could be the person himself or herself. The court in this instance is the regional circuit court. A proposal that a specialist multi-disciplinary tribunal should be established to hear these applications was not adopted⁶⁵. There are eight circuits with scheduled sittings at several locations in each circuit. Again, there are certain notice parties who must be made aware of the application⁶⁶. Part 5 provides for a flexible scheme of legal aid to ensure that the person has representation throughout the court process⁶⁷. Where the relevant person has no other representation, the court may direct the Director to appoint a 'court friend' to access the necessary information and 'promote the will and preferences of the person in court'⁶⁸.

The court may declare that the person lacks capacity in respect of one or more specified matters, unless a suitable CDM can be made available. The court may also declare that the person lacks capacity in respect of specified matters even if a CDM is made available⁶⁹. The relevant person may apply for a review of this declaration at any time and the court must in any case periodically review the declaration⁷⁰.

Where the court finds that a CDMA it not viable, the court may proceed to make the decision if it is urgent 'or otherwise expedient' to do so, or may appoint a decision-making representative (DMR)⁷¹. It is anticipated that the court may prefer to make the order itself when it is an isolated decision, on the basis that this will be quicker and less restrictive than appointing a substitute decision-maker. The court must also have regard to a number of matters when appointing a DMR, including the known will and preferences of the person, the desirability of preserving existing family relationships and the complexity of the relevant person's affairs⁷².

In the event that there is no suitable DMR available, the court shall appoint a DMR from a panel of persons maintained by the Director⁷³. In all cases, the order must be as limited as possible in duration and scope⁷⁴ and it may be varied or discharged on the court's motion or on application by the person or another party⁷⁵.

The DMR must submit regular reports annual reports to the Director, detailing all transactions, costs and expenses within the scope of the order⁷⁶.

⁶⁴ Section 36 (1) 2015.

⁶⁵ Oireachtas Library and Research Service, *Assisted Decision-Making (Capacity) Act 2015: how will it work?* (16 May 2017) p. 15.

⁶⁶ Section 36(2) 2015.

⁶⁷ Section 52 2015.

⁶⁸ Section 36(9)(c) and section 100 2015.

⁶⁹ Section 37 2015.

⁷⁰ Section 49 2015.

⁷¹ Section 38(2) 2015.

⁷² Section 38(5) 2015.

⁷³ Section 38(7) 2015.

⁷⁴ Section 38(9) 2015.

⁷⁵ Section 38(14) 2015.

⁷⁶ Section 46 2015 2015.

As with CDMA's, the Director maintains a register of DMRO's, searchable on the same basis⁷⁷.

The DMR acts as the *agent* of the relevant person, taking authority from the order of the court and shall, 'insofar as this is possible, ascertain the will and preferences of the relevant person and assist the relevant person with communicating such will and preferences'⁷⁸.

ADVANCE PLANNING: ENDURING POWERS OF ATTORNEY AND ADVANCE HEALTHCARE DIRECTIVES

Advance planning is regarded as an essential tool to support autonomous decision-making and ensure minimal intervention. As mentioned, it is already possible for a person to plan ahead by executing an enduring power of attorney, to be registered when the person loses capacity. Under the 2015 Act, the range of decisions which an attorney may be authorised to take is expanded to include healthcare decisions, up to but not including decisions in respect of life-sustaining treatment. The power may be general or specific in scope⁷⁹.

Under the 2015 Act, the attorney will have to submit detailed reports to the Director, commencing with a full statement of the donor's assets and liabilities within three months of registration and at 12 monthly intervals thereafter⁸⁰.

Similarly to CDMA, there are requirements around notification of certain parties and supporting documentation to include capacity statement by one medical and another healthcare professional at the time of execution and registration⁸¹. Again, the Director will maintain a searchable register of EPAs⁸².

ADVANCE HEALTHCARE DIRECTIVES (AHD)

A key change prior to enactment of the 2015 Act was the addition of a new part to provide for advance healthcare directives⁸³. The Department of Health drafted this part of the Act, following a public consultation process in 2014.

The Act restates the fundamental principle of the right to refuse medical treatment so that a person,

⁷⁷ Section 45 2015.

⁷⁸ Section 41 2015.

⁷⁹ Section 59 2015.

⁸⁰ Section 75 2015.

⁸¹ Section 60(1)(c) and (d) and Section 68(7)(b) and (c) 2015.

⁸² Section 72 2015.

⁸³ Part 8 2015 (sections 82-93).

“who has attained the age of 18 years and who has capacity is entitled to refuse treatment for any reason (including a reason based on his or her religious beliefs), notwithstanding that the refusal appears unwise, not based on sound medical principles or may result in his or her death”⁸⁴.

By making advance healthcare directive, people are enabled to ensure that their voices can be heard when they have lost capacity and to enable them to be treated according to their will and preferences⁸⁵. The Act distinguishes between a *refusal* of treatment, which is binding, if certain conditions are met, and a *request* for treatment which shall be taken consideration⁸⁶. An AHD may apply to refusal of life-sustaining treatment but not to the refusal of ‘basic’ care which is defined to include warmth, shelter, oral hydration and nutrition and hygiene measures⁸⁷. There is a role for the courts to adjudicate in the event of any ambiguity as to the validity or applicability of an AHD⁸⁸.

An AHD must be made voluntarily while the directive-maker has capacity but there is no requirement that it is supported by as capacity assessment⁸⁹. There is also no requirement that the AHD is registered in order to be effective. In response to a consultation in 2018, clinicians were strongly in favour of an accessible register of AHDs.

The 2015 Act allows the directive-maker to appoint in his or her AHD a ‘designated healthcare representative (DHR) to act as is or her agent and to ensure that the terms of the directive are respected⁹⁰. The DHR may be conferred with the power to advise and interpret the directive-maker’s will and preference regarding treatment and/or the power to consent to or refuse treatment based on the known will and preferences of the directive-maker by reference to the AHD⁹¹.

There is a significant exception, in that AHD is not applicable to refusal of mental health treatment when the directive-maker is an involuntary patient under the Mental Health Act⁹². The directive-maker may still however rely on his or her AHD to refuse physical health measures. This has been criticised as discriminatory. At time of writing, an amending bill has been progressed to remove this exclusion⁹³. In the parliamentary debates on this bill, one Senator has commented:

⁸⁴ Section 83(2) 2015.

⁸⁵ Section 83(1) 2015.

⁸⁶ Section 84(3) 2015.

⁸⁷ Section 85(4) 2015.

⁸⁸ Section 89 2015.

⁸⁹ Section 85(1) 2015.

⁹⁰ Section 87(1) 2015.

⁹¹ Sections 88 2015.

⁹² Section 85(7).

⁹³ Assisted Decision-Making (Capacity) (Amendment) Bill 2019.

*"[Under the Act as presently worded], one can refuse antibiotics but one cannot refuse antipsychotics. This exception offends against parity between physical and mental health and it overlooks the fact that those with mental ill health...are often accomplished experts in their own care."*⁹⁴

There are some features common to all the three tiers on the framework (DMAs, CDMs and DMRs) and to attorneys and DHRs. All are bound by the guiding principles. The 2015 Act also sets out common eligibility and disqualification or nullity criteria. In broad terms, a person cannot perform any of these five functions if he or she has certain criminal convictions or is the provider of residential services to the relevant person, or if he or she enters into a support arrangement under the Act. A person's spouse or partner is disqualified if the marriage or civil partnership ends, unless the arrangement provides otherwise⁹⁵. All five functions are also subject to a complaints and investigation process by the Director⁹⁶. The Act sets out a number of criminal offences relating to the use of fraud or undue influence to cause someone to enter into an arrangement⁹⁷. There is also an overarching offence of ill-treatment or wilful neglect applicable to all five functions, with penalties up to five years' imprisonment and or a fine of €50,000⁹⁸.

The 2015 Act sets out a number of areas of non-applicability. None of the arrangements can be engaged to supply consent to marriage, divorce, sexual relations or the placing of child for adoption or to enable a relevant person to serve as juror⁹⁹.

ESTABLISHMENT OF THE DECISION SUPPORT SERVICE

An earlier draft of the 2015 Act created the office of 'Public Guardian'¹⁰⁰. This was replaced by 'Director of the Decision Support Service'. It had been argued that 'guardian' carried associations of paternalism and was contrary to the ethos of the Act¹⁰¹. It had never been proposed that the Public Guardian would have a role as substitute decision-maker.

The Director of the Decision Support Service is bound by the guiding principles. The principal functions of the Director are set out in Part 9 of the Act. These might be broadly summarised as duties to promote awareness, provide information, supervise compliance and investigate complaints¹⁰². There is also

⁹⁴ Senator Colette Kelleher, Seanad Debates 23 October 2019.

⁹⁵ Sections 11, 12, 18, 20, 39, 40, 65, 66, 87.

⁹⁶ Section 96 2015.

⁹⁷ Sections 34, 80 and 90 2015.

⁹⁸ Section 145 2015.

⁹⁹ Section 138 2015.

¹⁰⁰ Section 24 Mental Capacity and Guardianship Bill 2008.

¹⁰¹ Joint Committee on Justice Defence and Equality Debate 22 February 2012.

¹⁰² Sections 95 and 96 2015.

a specific duty to act as central authority¹⁰³ for the purposes of the Convention on the International Protection of Adults¹⁰⁴ ('the Hague Convention').

As part of awareness-raising, the Director is required to promote public awareness of the CRPD¹⁰⁵. This is the only mention of the CRPD in the Act. There has been some commentary that more detailed, express referencing would have been appropriate, given that the Act is intended to give effect to CRPD¹⁰⁶.

The Director is enabled under the Act to publish a suite of codes of practice to provide guidance to DMAs, CDMs, DMRs, attorneys and DHRs and also to professionals, including health and social care professionals, legal practitioners and financial service providers¹⁰⁷. It is intended that the codes will make the 2015 Act more accessible and will provide advice in relation to scenarios that may arise. It is certain, however, that the codes will not contain all the answers in every situation.

OUTSTANDING ISSUES

There are two significant matters which at one stage were to be included in the 2015 Act but are not contained in the legislation as enacted.

Deprivation of Liberty Safeguards

It had been intended that the 2015 Act would be amended to include protections around the deprivation of liberty. A framework is required to deal with instances where someone who lacks the capacity to consent is effectively detained. At present no such framework exists and it is acknowledged that significant numbers of people in various services are 'under continuous supervision and control and not free to leave'¹⁰⁸. Individuals may be happy and compliant though non-consenting or they may be very much opposed to their living arrangements. They may change their minds or their attitude could fluctuate. Whatever their circumstances, they have no access at present to any independent authorising or reviewing body.

At present the Department of Health is developing a standalone bill. It is understood that this will provide for *protection* of liberty rather than deprivation of liberty safeguards and this is to be welcomed.

¹⁰³ Section 113 2015.

¹⁰⁴ Agreed at The Hague 13 January 2000.

¹⁰⁵ Section 95(1) 2015.

¹⁰⁶ See ORDINAIRE, Louise, "Who Decides now and to What Extent? A Critical Reading of the Assisted Decision-Making (Capacity) Act 2015", *Hibernian Law Journal*, Vol. 16, 2017, p. 95.

¹⁰⁷ Section 103 2015.

¹⁰⁸ Definition adopted by the UK Supreme Court in *P.v. Cheshire West and Chester Council and Anor* [2014] UKSC 19.

Informal Substitute Decision-Making

As mentioned above, the Act does not provide at all for informal substitute decision-making. There was provision in an earlier draft for informal decision-making in personal welfare matters¹⁰⁹. The section, similarly to section 5 of the Mental Capacity Act 2005 in England and Wales¹¹⁰ would have indemnified from liability an 'informal decision-maker' who made decisions in personal welfare matters outside of the framework of the Act. Given the broad definition of personal welfare, the informal decision-maker would have been free to make wide-ranging decisions concerning where a person would live and with whom they should have contact, admission to residential services, travel, and medical treatment, not including life-sustaining treatment.

Speaking in 2015, the Minister at the time stated that the intention had been to protect persons from liability where they took decisions in good faith and that the primary target group for these provisions was intended to be health care professionals. She said that the consideration was also given to family, friends or neighbours who might have to take decisions on behalf of a person at a time of emergency.

There was widespread opposition to this provision, which was seen as creating a separate category of decision-makers, free from the scrutiny of the Decision Support Service and the courts. It was argued that it would be a disincentive to people to create formal arrangements, that it would create uncertainty for all parties and undermine the ethos of the Act. In response to these arguments, the section of the Bill was removed entirely¹¹¹.

The removal of an exemption around informal decision-making leaves unanswered the question of what a health and social care professional is to do when faced with a non-emergency decision, where (after all efforts have been exhausted), the person lacks capacity to consent to a proposed measure and no formal supports are in place.

In the UK, prior to the Mental Capacity Act, the House of Lords had already held in relation to healthcare measures that the defence of necessity is not confined to emergency situations. There has been no examination of this issue by the Irish courts. Donnelly suggests that courts here might take a similar view. This would mean that the doctrine of necessity might reasonably be considered to apply in non-emergency situations to exempt from liability a professional who has complied with appropriate standards and with the guiding principles under the Act¹¹². It is also possible that, if necessity as presently understood does not apply because the situation is not an emergency

¹⁰⁹ Section 53, Assisted Decision-Making (Capacity) Bill 2013.

¹¹⁰ Section 5 Mental Capacity Act 2005: *Acts in connection with care or treatment*.

¹¹¹ Minister Kathleen Lynch, Select Committee on Justice Equality and Defence Debate 17 June 2015.

¹¹² DONNELLY, Mary, "The Assisted Decision-Making (Capacity) Act 2015: Implications for Healthcare Decision-Making", *Medico-Legal Journal of Ireland*, Vol. 22, n.º 2, 2016, p. 65-74.

and time is not of the essence, the court may be reluctant to endorse a process outside of the formal framework of the Act.

CRPD: COMPLIANCE OF THE 2015 ACT WITH ARTICLE 12

The CRPD was opened for signature in 2007 and entered into force in 2008. It is the first international treaty dedicated to the rights of persons with disabilities. Article 1 sets out the core purpose of the CRPD, which is

“to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”

Disability is non-exhaustively defined according to a social model. This model views a person as not inherently disabled but rather experiencing disability as a result of environmental and societal structures, which fail to accommodate his or her impairment¹¹³. Commentary on CRPD refers to (at least) two paradigm shifts. These are the shift in perspective from viewing disability as a medical/ biological problem to viewing society’s response as the problem and the shift from viewing people with disabilities as objects of charity or welfare to viewing them as rights-holders¹¹⁴. Quinn summarises it as the ‘deceptively simple proposition that persons with disabilities are ‘subjects’ and not ‘objects’- sentient beings like all others deserving equal respect and equal enjoyment of their rights’¹¹⁵.

Article 12, guaranteeing equal recognition before the law has been described as the key to delivery of the rights set out in the other articles of CRPD¹¹⁶. Quinn refers to it as ‘a sword to forge our way’¹¹⁷. Article 12.2 provides that:

“States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.”

¹¹³ Some commentators argue that ‘disabled people’ is terminology more consistent with the social model. See PEARL, Alex L, “Article 12 of the United Nations Convention on the Rights of Persons with Disabilities and the Legal Capacity of Disabled People: The Way Forward?”, *Leeds Journal of Law and Criminology*, Vol. 1, No.1, 2013 p. 3.

¹¹⁴ Series L., *The Small Places: New to the UN CRPD* (accessed February 2020).

¹¹⁵ QUINN, Gerard, “Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD”, *Harvard Law School: Project on Disability*, 20 February 2010 p. 68.

¹¹⁶ KEYS, Mary, “Legal Capacity Law Reform in Europe: An Urgent Challenge”, in QUINN, Gerard; WADDINGTON, Lisa (Eds), *European Yearbook of Disability Law*, Vol. 1, Oxford: Intersentia, 2009, p. 59.

¹¹⁷ Supra note 115 at p. 73.

At the time of ratification in March 2018, Ireland entered a declaration, and reservation in relation to Article 12, similar to those of Australia, Canada and Norway, stating:

“Ireland recognises that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. Ireland declares its understanding that the Convention permits supported and substitute decision-making arrangements which provide for decisions to be made on behalf of a person, where such arrangements are necessary, in accordance with the law, and subject to appropriate and effective safeguards. To the extent that article 12 may be interpreted as requiring the elimination of all substitute decision making arrangements, Ireland reserves the right to permit such arrangements in appropriate circumstances and subject to appropriate and effective safeguards.”

Ireland has not yet ratified the Optional Protocol which allows the Committee for the CRPD to examine individual complaints against state parties. At the time of ratification, the government indicated its intention to ratify the Protocol in due course. The Irish Human Rights and Equality (IHREC) has been appointed under Article 33 to review Ireland’s implementation and monitoring of the CRPD and to report to the UN Committee under Article 35. IHREC has convened a Disability Advisory Committee, comprising a majority of people with disabilities to assist in this monitoring function.

Legal capacity is not defined in the CRPD. Donnelly refer to the language of Article 12 as ‘opaque’ and its precise requirements unclear¹¹⁸. In 2010, Quinn also referred to the ‘constructive ambiguity’ of the CRPD as being necessary to achieving agreement but stated that ambiguity sometimes ‘postpones a reckoning’¹¹⁹.

To resolve ambiguity and provide further guidance on Article 12, the UN Committee conducted interactive forums and published its General Comment No. 1 (GC1) in 2014. General Comments are not legally binding but influential.

In GC1, the Committee distinguishes inherent legal capacity from mental capacity and states that:

“Legal capacity is the ability to hold rights (legal standing) and to exercise rights (legal agency).”¹²⁰

Persons with disabilities are therefore confirmed as legal persons before the law and also legal actors, entitled to have their actions recognised by law. In Part III of GC1, the Committee sets out a list of obligations necessary to

¹¹⁸ Supra note 112 at p. 66.

¹¹⁹ Supra note 115 at p. 69.

¹²⁰ Committee on the Rights of Persons with Disabilities, *General Comment No.1: Article 12: Equal Recognition Before the Law*, 11th Session May 2014 para. 13.

the recognition of 'universal legal capacity'¹²¹. The 2015 Act might be said to score quite highly in relation to some aspects of Part III. The 2015 Act replaces best interests with guiding principles which emphasise respect for will and preferences; it provides safeguards including mechanisms for objections and complaints in relation to decision support arrangement; it provides for legal recognition of a person's chosen decision supporter; it permits a person to revoke or vary a decision support arrangement.

However, the 2015 Act may be seen as non-compliant with two of the obligations asserted in GC1. These are the obligations to replace all forms of substituted decision-making with supported decision making and to ensure that access to supported decision-making is not based on an assessment of 'mental capacity'. The second of these will be considered first.

ARTICLE 12 AND FUNCTIONAL ASSESSMENT OF CAPACITY

Gooding writes that the functional assessment evolved from a developing human rights approach to capacity. It recognises that people can be 'a bundle of capacities' and was seen as facilitating a proportionate, minimally restrictive approach and a departure from the binary or status-based approach of plenary guardianship¹²². In 2008, the functional approach was endorsed by the ECtHR in *Shtukaturov v. Russia*¹²³. The ECtHR held that it was insufficient for a court to rely solely on a medical finding of schizophrenia to conclude that the applicant could not understand his actions. The ECtHR noted that the report did not explain *what kind of* actions the applicant was incapable of understanding.

Since then, however, there has been a shift away from support for the functional test, in some of the literature if not in law and policy. The argument is that functional assessment is in effect a functional assessment of *mental capacity* in that it measures cognition, rationality and intellectual ability¹²⁴. Speaking in 2014 about Northern Ireland's planned capacity legislation, Michael Bach characterised the functional approach in this way:

*"The professional would look at what's going on inside a person's head, what sort of talent this individual has to make decisions, and how well he or she is communicating it. That may have been an enlightened starting point a few decades ago, but we now live in a human rights-based era which guarantees autonomy for all."*¹²⁵

¹²¹ Ibid para 24 -30.

¹²² Supra note 52 at 155-156.

¹²³ Application No. 44009/05 27 March 2008 para. 93.

¹²⁴ Supra note 52 at p. 159.

¹²⁵ BACH, M. and LEWIS, O., "How Northern Ireland can avoid making a big 'mental capacity law' mistake", presented at a seminar organised by *Mencap Northern Ireland and the Northern Irish Association for Mental Health*, 20 March 2014 (blogpost accessed February 2020).

GC1 states that mental capacity is not an objective or scientific phenomenon but depends on social and political context and ‘on the disciplines, professions and practices which play a dominant role in assessing mental capacity’¹²⁶. Alex Ruck Keene has written that capacity is inescapably ‘in the eye of the beholder’ and that assessors should be aware of their own values and pre-conceptions¹²⁷. There is an apprehension that an assessor may be disposed to find what they need to find in order to justify a particular course of action.

Bach also states that a rebuttable presumption of capacity, the first of the guiding principles in the 2015 Act, is meaningless and fails to guarantee rights¹²⁸.

The text of the CRPD does not address the assessment of capacity at all. Before GC1, some commentary found that Article 12 endorsed the functional approach¹²⁹. GC1 however unambiguously rejects the functional approach, stating that it ‘attempts to assess mental capacity and deny legal capacity accordingly’¹³⁰. GC1 also states that the functional assessment is indirectly discriminatory. The argument is that, even if the wording is disability-neutral, as in the 2015 Act, it is a test which a person with a disability is more likely to fail than a person without a disability. Bach has written that the functional assessment imports ‘ableist assumptions about what the demonstration of decision-making ability entails’¹³¹.

As noted above, under the 2015 Act, the first step is not to assess capacity. It arises only when every effort has been made to involve the person in the decision-making and to facilitate an independent decision by all available means. The general principles are intended to ensure that this happens.

One of the most progressive features of the 2015 Act is the provision for gradations of support. Therefore, it may be argued that the purpose of assessment when it arises is to match the person and the decision to the appropriate level of intervention on the framework. Thus, a CDM is appropriate when the person has the capacity to appoint a CDM and will have the capacity together with the CDM to make the decision; a DMR may be appointed by the court only when a CDM will not suffice in respect of a particular decision. Gooding writes that the Canadian Association of Community Living in its submission on the draft GC1 argued that functional assessments of mental capacity can help to identify those who exercise their legal capacity in different ways and to set the boundaries between different levels of support. The CACL stated that:

¹²⁶ GC1 para 14.

¹²⁷ RUCK KEENE, Alexander Charles Edward, “Is Mental Capacity in the Eye of the Beholder?”, *Advances in Mental Health and Intellectual Disabilities*, Vol. 11, No. 2, 2017, p. 30-39.

¹²⁸ Supra note 125-39.

¹²⁹ Supra note 114 at p. 13.

¹³⁰ GC1 para. 15.

¹³¹ BACH, Michael; and KERZNER, Lana, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity* (Report to the Law Commission of Ontario) (2010) p. 66.

*"To recognize that people have different decisional abilities is not in itself discriminatory; just as it is not discriminatory to recognize that people have different mobility abilities"*¹³².

However, GC1 is emphatic that, while support must be tailored to individual needs, access to support should not be determined by capacity assessments and instead alternative, non-discriminatory indicators of support are needed¹³³. There is no elaboration in GC1 as to what these alternative indicators would look like. Gooding refers to joint submissions to the Australian Law Reform Commission which propose testing the 'functional ability of the *supports*' to meet the requirements of a person to make and/or communicate a decision¹³⁴. This does not appear to have been progressed as a model.

It is arguable that an assessment of capacity cannot be avoided in the particular context of advance planning. How can it be determined that an advance healthcare directive or enduring power of attorney is to come into effect without engaging with a person's current capacity? Flynn and Arstein-Kerslake state that in order for an enduring power of attorney to be compliant with Article 12, it should not become operational on the basis of an assessment of mental capacity and that instead the individual should be able to set her own parameters for when a power of attorney enters into force¹³⁵. This is a departure from established understanding of how advanced planning works. It is difficult to envisage circumstances in which an EPA could become effective that do not take any account of the donor's ability to take the relevant decisions by herself.

Some commentators have argued that the rejection of capacity assessments is simply unrealistic. Kim states that it is "just a basic fact that some people cannot take decisions for themselves in any commonly accepted sense of the word 'decision' and that capacity assessments are necessary to determine decisional authority "because there is no choice in the matter"¹³⁶. It is this writer's experience that many health and social care professionals would be likely to agree.

Clough argues that, while assessments of capacity are rejected as failing to apply societal context and to take account of a person's broader circumstances, insistence on an exclusively supported decision-making model can be similarly reductive:

¹³² Supra note 52 at 231.

¹³³ Para 29(i).

¹³⁴ Supra note 52 Gooding 232.

¹³⁵ ARSTEIN-KERSLAKE, Anna and FLYNN, Eilionóir, "The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A Roadmap for Equality Before the Law", *The International Journal of Human Rights*, Vol. 20, Issue 4, 2016 at note 33.

¹³⁶ CRAIGIE, Jillian et al, "Legal Capacity, mental capacity and supported decision-making: Report from a panel event International", *Journal of Law and Psychiatry*, Vol. 62, 2019, p. 160-168, (164-165, Kim, S. at para 6.2).

*"We inadvertently reinforce the idea that an individual, at a particular moment in time is deficient and that we can support them to reach the required level of understanding to achieve autonomy."*¹³⁷

ARTICLE 12 AND THE ABOLITION OF SUBSTITUTE DECISION-MAKING

Article 12 does not state that substitute decision-making in all its forms should be abolished. This was a divisive proposition when the CRPD was being drafted, with some states negotiating for explicit retention of substitute decision-making, subject to safeguards, while disability rights groups argued for an exclusive supported decision-making model¹³⁸. Dhanda writes that Article 12(4) was conceived as a compromise, combining 'some of the standards for guardianship with some of the standards for supported decision-making'¹³⁹. GC1 is uncompromising, however, and makes clear that states must take steps immediately to replace substitute decision-with supported decision-making and the development of supported decision in parallel to substituted decision-making is non-compliant with Article 12¹⁴⁰. GC1 states that the safeguards envisaged by Art 12(4) are not an endorsement of some substitute decision-making and are primarily safeguards to ensure respect for the person's rights will and preferences¹⁴¹.

GC1 sets out the unacceptable features of substitute decision-making systems. These are defined as systems where legal capacity is removed, even in respect of a single decision; a substitute decision-maker can be appointed by someone other than the person against the person's will and any decision made by a substitute decision-maker is based on best interests' of the person, as opposed to being based on the person's own will and preferences¹⁴².

Flynn and Arstein-Kerslake propose an alternate model, aligned with the requirements of GC1¹⁴³.

- i. The first tier is legally independent decision-making, with assistance as required.
- ii. The second tier is a formal or informal 'circle of support'. Supporters should know the person, help interpret their will and preference and

¹³⁷ Supra note 25 at p. 273.

¹³⁸ Supra note 114 p. 15.

¹³⁹ DHANDA, Amita, "Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?", *Syracuse Journal of International Law and Commerce*, Vol. 34, 2007, pp. 429-462 (448).

¹⁴⁰ GC1 para 28.

¹⁴¹ GC1 para 20.

¹⁴² GC1 para 27.

¹⁴³ FLYNN Eilíonor; ARSTEIN-KERSLAKE Anna, "Legislating Personhood: realising the right to support in exercising legal capacity", *International Journal of Law in Context*, Vol. 10, N° 1, 2014, p. 95.

communicate these to third parties who must then accept the decision as valid.

- iii. The third tier is *facilitated* decision-making, which applies as a last resort only where it has not been possible to interpret the will and preferences of the person. An appointed facilitator has the task of ‘imagining’ what the person’s will and preferences might be and deciding on that basis.

GC1 endorses this ‘best interpretation of will and preferences’ approach in order to achieve facilitated decision-making¹⁴⁴.

Looking at GC1’s analysis of the ‘bad’ features of substitute decision-making and the above model of what a ‘good’ replacement looks like, the 2015 Act does not score perfectly. The lowest tier support, the DMAA, broadly seems to meet the standard, there are some deficiencies around supported decision-making and the upper tier of decision-making representation would probably be non-compliant, necessitating Ireland’s reservation.

In relation to mid-tier decision supports, GC1 states that there must be legal recognition of the person’s chosen supports and the 2015 Act clearly provides for this. However, GC1 goes further and requires states to facilitate the creation of supports for people who may not have naturally occurring support in the community¹⁴⁵. There is nothing in the 2015 Act about arranging these supports for persons who do not have them. There are obvious attractions to the idea of mobilising support to ensure that a person with disability is enabled to exercise their capacity. The model for the delivery by the state of such support is not clear from GC1 or the literature.

As mentioned above, under the 2015 Act, residential service providers are not eligible to act as DMAs or CDMs for persons in their care and persons who have support arrangements of their own may not act as supporters to other people. Service providers have commented to this writer on the limitations which these criteria may impose. It could mean that a person with a disability in residential services cannot call on the trusted people closest to them to become their decision supporters. Families and communities in Ireland may be comparatively close-knit but this is probably becoming less and less true. As mentioned, in approximately one third of current wardship cases, the General Solicitor has been appointed as committee, in the absence of any suitable relation or friend. This may be indicative of the proportion of persons who will have nobody available to provide mid-tier support under the 2015 Act.

The 2015 Act does not use the expression substituted decision-making, preferring instead to ‘representative’ and ‘agent’. However, decision-making under Part 5, whether by the court or by a DMR following a declaration of incapacity, would seem inescapably to fall within the definition of substitute

¹⁴⁴ GC 1 para 21.

¹⁴⁵ GC1 para 29(d).

decision-making. There is no attempt in the 2015 Act to re-imagine the process as ‘facilitated decision-making’.

The 2015 Act also retains another ‘bad’ feature of substitute decision-making, as defined by GC1, in that the court is the appointer of the DMR and the DMR takes authority from the court order. Also, while the 2015 Act requires the court to have regard to the relevant person’s wishes and the importance of maintaining relationships, the court may appoint a DMR previously unknown to the relevant person, if there is no other suitable DMR available. It is hoped that the supervision process, periodic reviews by the court and the code of practice for DMRs will ensure as far as possible that the relationship between the DMR and relevant person works well.

The 2015 Act might be seen as compliant with Article 12 in that the court and the DMR are bound to give effect in so far as practicable to the relevant person’s will and preferences and there is no mention of best interests. However, on a reading of GC1, it would appear to be an inherently contradictory requirement that a substitute decision-maker must give effect to the relevant person’s will and preferences. GC1 interprets Article 12 to mean that, if a person’s will and preferences can be discerned, then there is no need for substitute decision-making.

COMMENTARY ON GC1 IN THE LITERATURE

The debate about GC1 has been robust, with critics querying whether perfect compliance is achievable or desirable. Criticism of GC1 has focused on its two central contentions, that all decision-making can be supported and that no decision which runs counter to will and preference is permissible. It is argued, sometimes in strong terms, that the position adopted by the Committee is disconnected from reality and can fail to serve the very people whose rights they seek to uphold.

Exclusively Supported Decision-Making

On the first point, the argument has been made that there are real life situations in which people just cannot decide in any meaningful way, however much support is made available. The usual example offered is of the person in a coma. Depending on the decision, it might also be true of a person with an acquired brain injury or advanced dementia who has not planned ahead or a person with a profound intellectual disability. GC1 is clear that,

“At all times, including in crisis situations, the individual autonomy and capacity of persons with disabilities to make decisions must be respected.”¹⁴⁶

¹⁴⁶ GC1 para 18.

Flynn and Arstein-Kerslake state that GC1 reflects a presumption that, even in the most difficult circumstances, it is almost always possible to arrive at some understanding of an individual's values, views and beliefs¹⁴⁷. There is perhaps a well-placed concern that if substitute decision-making is retained as an option, we might give up early in trying to support a person to make and communicate a decision. However, there will always be hard cases. Quinn cautions against creating a credibility problem by 'stretching the fiction of 100% support'¹⁴⁸. Bach writes that the model which says that if individuals are just given enough time and support they will be able to make their will and preference known, 'fails the reality test'¹⁴⁹.

It is argued that calling substitute decision-making supported decision-making does not make it so and it is important to acknowledge when a decision is being made *for* someone rather than *by* or *with* someone¹⁵⁰. Otherwise, there is a risk that the sort of informal substitute decision-making which was rejected in the 2015 Act will continue in the guise of supported decision-making arrangements.

It has been written that the 'best interpretation' of the person's will and preference approach is not without problems. Scott Kim points out that, when we decide about the adequacy of decision supports for a person or apply an interpretation of will and preference, we are already deciding things about and for the person¹⁵¹. Donnelly writes that the problem with best interpretation is that there are things that we do not and cannot know about a person and so when we make decision for someone, we must own up to it, rather than engage in subterfuge¹⁵². In this way decision-making can be made accountable and, it is hoped, the well-documented potential for abuse should be reduced. There is also the point that third parties (for example lawyers, healthcare professionals) are entitled to know who in reality they are transacting with so that they can be assured that contracts and consent are valid.

In the debate around the abolition of substitute decision-making, there is a noticeable sensitivity around language and a tendency to attach new meanings to words and concepts which have a recognised meaning in law or even ordinary language. 'Agency', 'autonomy', 'understanding', 'intention' and 'capacity' itself have been re-imagined in various ways. It might be argued that non-disabled people have controlled the narrative for too long and that a new vocabulary is timely. However, it is probably useful to step back and think about what we are trying to achieve when, for example, we call something that looks very like substitute decision-making, 'facilitated decision-making'.

¹⁴⁷ Supra note 135 at para 4.2.2.

¹⁴⁸ Supra note 115 at p. 77.

¹⁴⁹ Supra note 131 at p. 164.

¹⁵⁰ Supra note 52 at p. 220.

¹⁵¹ Supra note 136 at para 6.2.

¹⁵² Supra note 44 at p. 327.

Flynn and Arstein-Kerslake write that what is required in line with GC1 is a faithful effort 'not to impose an outside decision which others think is in the person's best interests, but to arrive at a decision as informed as it possibly can be by the individual's own will and preferences'¹⁵³. This in fact sounds quite close to the duties of a DMR under the 2015 Act, although the Act makes no claim that the DMR's role is to facilitate decision-making.

Some have expressed the fear that the retention of substitute decision-making, in the 2015 Act will undermine supported decision-making and the Act will therefore fail to deliver wholesale reform. The interpretation by the courts of the Mental Health Act 2001 is offered as a cautionary tale¹⁵⁴. The report of the Expert Group Review of the Mental Health Act (MHA) found that even though the right of the person to dignity, bodily integrity, privacy and autonomy is clearly stated in the MHA, the fact that 'best interests' was retained as a principal consideration led the courts to default to a paternalistic interpretation¹⁵⁵. It will be important that any intuitive preference for substitute over supported decision-making is monitored and curtailed.

Primacy of will and preferences

On the inviolability of will and preference, frequently asked questions tend to ask 'what if?'. GC1, which does not provide a definition for will and preferences, does not offer answers to these dilemmas. What if past will and preferences and present will and preferences are two different things? Is there a distinction between will and preference and what if these are in conflict? Does 'will', if it refers to a person's 'masterplan' supersede preferences? These are complex ethical questions for a decision supporter.

What if what the person wants to do is going to result in serious harm? According to Flynn and Arstein-Kerslake, that there would be no obligation to support a person in the exercise of their capacity if it would give rise to civil or criminal liability. However, they state that, if an action is lawful, then the fact that serious harm may result is, 'does not equate to a justification for failure to respect will and preferences'¹⁵⁶. In the experience of this writer, this would appear highly problematic to many potential future decision supporters and professionals who will engage with the 2015 Act. For this group, the balance between empowering people in their care and safeguarding them from harm is complex. As Series writes:

¹⁵³ Supra note 135 para 4.2.2.

¹⁵⁴ Supra note 22 at p.25.

¹⁵⁵ Department of Health, Report of Expert Group on the Review of the Mental Health Act 2001 (2014) p. 12.

¹⁵⁶ Supra note 135 para 4.2.1.

*"Everyone must have their freedom and nobody must get hurt or die. But we cannot have it both ways. Somebody, somewhere decides. And these are not comfortable decisions to make."*¹⁵⁷

The non-interventionist argument is that if the state would not intervene in the exercise of legal capacity by a person who does not have disabilities, then the state should not apply a differential standard and intervene in the exercise of legal capacity by a person who has a disability. There are counter arguments that equality must mean more, that being disabled *is* different and that discrimination consists of failing to acknowledge and accommodate that difference. Commentators have written that in focusing on will and preference, there is risk that we can lose sight of much else, that it is a narrow conceptualisation of autonomy¹⁵⁸ and that it would be more profitable to consider what it means to uphold a person's dignity. Donnelly submits that,

*"Just as indifferent disregard to will and preference fails to respect a person's dignity, an indifferent accession to will and preference, an indifferent accession to will and preferences may also fail to respect his or her dignity."*¹⁵⁹

Lewis has also written that if we are preoccupied with ensuring that a person's wishes and feelings are determinative, we risk displacing other important values such as health, wellbeing, happiness, a pain-free life and the right to non-discrimination¹⁶⁰. On safeguarding, Mr. Justice Munby very quotably posed the question in the Court of Protection (England and Wales),

*"What is the point of making someone safe if in doing so you just make them miserable?"*¹⁶¹

Turning this around, some commentators might say,

"What is the point of respecting a person's will and preference, if ultimately you only make them more miserable?"

There is also the argument that by upholding the free exercise of choice above everything else, you 'let the state off the hook'. Clough writes that by enforcing the ideas of individual responsibility we can obscure structural and institutional inequalities and that 'the CRPD does and must amount to more than a right to left alone'¹⁶².

¹⁵⁷ Series, L. *The Small Places* 14 November 2014.

¹⁵⁸ Supra note 125, LEWIS, O. at p.165.

¹⁵⁹ Supra note 44 at p. 325.

¹⁶⁰ Supra note 125, Lewis, O. at p.165.

¹⁶¹ *MM v Local Authority X* [2007] EWHC 2003.

¹⁶² Supra note 25 at p. 275.

In 2018, Lewis commented on GC1 that it was unprecedented in international human rights law for a treaty body to articulate as a norm something that is not reflected in the law anywhere¹⁶³. At the time of writing, it has been tentatively suggested¹⁶⁴ that the Committee may have softened its position. In late 2019, the Committee published its concluding observations¹⁶⁵ on its second report on Australia's compliance with the CRPD. The Committee recommends the implementation of the supported decision-making framework proposed in a 2014 report by the Australian Law Reform Commission (ALRC)¹⁶⁶. In its report the ALRC states that there is no discriminatory denial of legal capacity inherent in a functional test, provided the emphasis is on providing decision-making support and protecting human rights¹⁶⁷. The ALRC report also recommends limited *representative* decision-making subject to safeguards, and envisages that the representative may override the person's will and preferences to protect the person's physical and mental integrity¹⁶⁸.

It is too early to say whether the Committee is changing direction. The first report on Ireland's compliance with the CRPD will be telling.

CONCLUSIONS

Scholarship makes a vital contribution to policy, policy informs legislation and then legislation has to be implemented in practice. The legislative and implementation processes can be so protracted (as this writer is well aware) that by the time an act comes to life, scholarship has moved on and started to say something else. What once appeared progressive is criticised for not shifting paradigms far enough. At time of writing, it is just possible that the debate has begun to circle back again.

The advantage of waiting almost 150 years to replace a system is that Ireland has had the opportunity of considering the long experience of many other jurisdictions. What is noticeable in the literature, though, is the absence of empirical evidence. There is much on what supported decision-making should look like but very little evaluation of outcomes where it has been implemented¹⁶⁹. There is an argument that if access to supported decision-making something is a *right*, there should be no obligation to prove that it 'works'¹⁷⁰.

¹⁶³ Supra note 44 at p. 325.

¹⁶⁴ KEENE, Alex Ruck, "The CRPD Committee and Legal Capacity — a step forwards?" mentalcapacitylawandpolicy.org.uk 14 October 2019 (accessed February 2020).

¹⁶⁵ *Committee on Rights of Persons with Disabilities*, "Concluding observations on the combined second and third periodic reports of Australia" (15 October 2019).

¹⁶⁶ *Ibid.* para 24(b).

¹⁶⁷ ALRC, *Equality, Capacity and Disability in Commonwealth Law* (2014), para 3.48.

¹⁶⁸ *Ibid.* para 3.83.

¹⁶⁹ See KOHN, Nina A; BLUMENTHAAL, Jeremy A; CAMPBELL, Amy T., "Supported Decision-Making: A Viable Alternative to Guardianship?", *Penn State Law Review*, Vol. 117, No 4, p. 1111.

¹⁷⁰ Supra note 52 at p.249.

However, there is no single agreed uniform approach to the delivery of these rights, and if we are going to implement large scale reforms, we need to know that what we design and build is fit for purpose. It has been acknowledged that persons with disabilities and their advocates made a significant contribution to the debate around the 2015 Act. It will be important that we continue to hear the voices of people who rely on the new framework in Ireland and do our best, though this will be challenging in the absence of comprehensive existing data, to evaluate it against the system that has gone before.

The 2015 Act is not perfect. It is not particularly accessible and, despite being already 146 sections long, it is incomplete. At time of writing, amending legislation to address some of its flaws is being progressed. Some of these amendments are procedural and technical and others will be more substantive. It is expected that one significant change will improve the position of current wards and their access to the court and to representation. However, it is the view of this writer that it is ambitious and deeply principled legislation. The drafters have done their best to reflect a range of expert views, to negotiate the requirements of the CRPD and to translate important human rights ideals into workable structures and processes.

There are compelling, learned and deeply-felt arguments around Article 12 and these must be acknowledged. Ultimately, it is probably not appropriate for this writer as Director to be drawn too much further into the debate. The 2015 Act presents considerable challenges in terms of planning, resourcing and re-education. It will be commenced and as an office-holder and 'intervener' this writer will have responsibilities to implement it as it is, while being alert to what works and what needs to be revisited.

Despite its limitations, it is submitted that the 2015 Act presents an opportunity for adults with disabilities to assert themselves at the centre of decision-making that affects them. Not long after I took up this post the 2015 Act was described to me as 'a huge disappointment' in terms of compliance with Article 12 CRPD. However, it has also been described by a young man with an intellectual disability as his 'act of emancipation' and it is surely better to begin in hope.