The Mental Capacity Act 2005, the Adults with Incapacity (Scotland) Act 2000 and the Convention on the Rights of Persons with Disabilities: The Basics

Background

1. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is renowned as a ground-breaking treaty, developed using a highly inclusive drafting process. Civil society organisations and disabled people’s organisations (DPOs), in particular, were involved alongside government representatives throughout the negotiations. The concept of ‘nothing about us without us’ was used by DPOs to frame the negotiation of the Convention. The CRPD now has a remarkably high number of signatories and ratifications – with 145 signatories and 158 ratifications in the six years after it entered into force. The CRPD does not create any new rights. Instead, it constitutes a comprehensive reformulation of existing human rights in the context of disability, and provides a clearer articulation of the pressing human rights concerns of people with disabilities.

2. The CRPD is monitored at the international level through its treaty body, the UN Committee on the Rights of Persons with Disabilities (CRPD Committee). This Committee is predominantly composed of persons with disabilities, nominated and elected by States Parties to the Convention (i.e. countries which have signed and ratified the Convention). The Committee reviews States Parties reports, and prepares Concluding Observations on these, providing further guidance to the States as to how compliance with the Convention can be achieved.

3. The CRPD is legally binding for all states that have signed and ratified, including the United Kingdom. The real power and value of the CRPD, however, lies in the hands of individuals who choose to
be agents of social change. The CRPD provides a framework that was created by and for people with disabilities and can be used as a guide to achieving universal rights protection for people with disabilities. Of particular relevance to the Mental Capacity Act 2005 and the Adults with Incapacity (Scotland) Act 2000 is Article 12 of the CRPD, which sets out the right to legal capacity on an equal basis with others.

The Right to Legal Capacity on an Equal Basis

4. The right to legal capacity on an equal basis was enumerated in the CRPD in Article 12 as a subsidiary to the right to equal recognition before the law. The Convention to Eliminate all forms of Discrimination Against Women (CEDAW), was the first international human rights instrument to enumerate the right to legal capacity on an equal basis in 1979 (Article 15). However, the right to equal recognition before the law can be found in the earlier Universal Declaration of Human Rights (UDHR) (Article 6) and the International Covenant on Civil and Political Rights (ICCPR) (Article 16). Article 12(1) recognises that persons with disabilities have the right to be recognised everywhere as persons before the law – applying the existing right to equal recognition before the law to the specific context of persons with disabilities.

5. The right to legal capacity on an equal basis in Article 12(2) CRPD encompasses both a ‘static’ and an ‘active’ element. The static element is the right to be a person before the law and a holder of rights. The active element is the right to be a legal agent whose decisions are respected and validated by the law.\(^1\)

6. The CRPD does not mention the term ‘mental capacity.’ However, ‘mental capacity’ is often used as a basis for granting or denying ‘legal capacity’ to individuals in respect of particular decisions. Most assessments of mental capacity include a determination about the individual’s impairment or disability. Since Article 12(2) requires the enjoyment of legal capacity to be equal for persons with and without disabilities – it calls into question any systems that deny legal capacity on the basis of disability or impairment. It also calls into question any system that is indirectly discriminatory against people with disability. The CRPD Committee has made clear that this indirect discrimination includes ‘facially neutral’ assessments of mental capacity that are disproportionately applied to people with disabilities (as shall be discussed below).

7. Article 12(3) of the CRPD introduces an obligation on states parties to ‘take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.’ The CRPD Committee has stated that support systems for the exercise of legal capacity must replace regimes of substituted decision-making that deny legal capacity.\(^2\) This becomes evident when

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\(^2\) See, for example, Consideration of reports submitted by States parties under article 35 of the Convention: Concluding observations, Tunisia, Committee on the Rights of Persons with Disabilities (CRPD), 5th Sess., at 4, U.N. Doc. CRPD/C/TUN/CO/1 (April 11-15 2011); Consideration of reports submitted by States parties under article 35 of the Convention: Concluding observations, Spain, Committee on the Rights of Persons with Disabilities (CRPD), 6th Sess., at 5, U.N. Doc. CRPD/C/ESP/CO/1 (September 19-23, 2011);
Article 12(3) is read in conjunction with Article 12 (1 and 2), which disallows substituted decision-making systems because they discriminatorily deny legal capacity to persons with disabilities.

8. Article 12(4) sets out safeguards required for all measures that relate to the exercise of legal capacity. These include the principle of proportionality, freedom from conflict of interest and undue influence and respect for the rights, will and preferences of the person. This section also states that safeguards should ensure that these measures ‘apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.’ At first glance some of these safeguards may read like those which exist for substituted decision-making systems that deny legal capacity. However, reading this paragraph in light of Article 12 as a whole, and consistently with the rest of the Convention, it becomes clear that substituted decision-making systems that deny legal capacity are a violation of Article 12. The safeguards in paragraph 4, refer to systems that are compliant with Article 12. Therefore, they are safeguards for situations where an individual is receiving support to exercise legal capacity.

9. Article 12(5) contains explicit recognition of the importance of the right to legal capacity for persons with disabilities in respect of financial and property matters. In acknowledging the discriminatory barriers which have prevented persons with disabilities from owning and inheriting property, and controlling their financial affairs, Article 12(5) requires States to take action to ensure that persons with disabilities have equal access to credit and are not arbitrarily deprived of their property.

The General Comment on Article 12 CRPD

10. The Committee’s General Comment (GC) No. 1 on Article 12 was adopted in April 2014. This follows over 5 years of debate within the Committee, a day of general discussion on Article 12 with the involvement of States Parties and civil society in October 2009, and the publication of a Draft of the General Comment in November 2013, and request for submissions from the public as to its content and direction.

11. The GC clarifies a number of core interpretative issues regarding Article 12. It provides for the first time, definitions of ‘support to exercise legal capacity’, and ‘substituted decision-making’. Support to exercise legal capacity is defined as follows:

Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making. Article 12, paragraph 3, does not specify what form the support should take. “Support” is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity.³

³ Consideration of reports submitted by States parties under article 35 of the Convention: concluding observations, Peru, Committee on the Rights of Persons with Disabilities (CRPD), 7th Sess., at 25, UN Doc CRPD/C/PER/CO/1 (April 16-20, 2012).
³ Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, Paragraph 15, UN Doc. No. CRPD/C/GC/1, adopted at the 11th Session (April 2014).
12. By contrast, substitute decision-making is defined as follows:

Substitute decision-making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where (i) legal capacity is removed from a person, even if this is just in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will or (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective “best interests” of the person concerned, as opposed to being based on the person’s own will and preferences.⁴

13. The GC also clarifies that the obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives. It clearly states that “the development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention.”

14. The GC also sets out the distinction between mental capacity and legal capacity, and makes some explicit comments regarding functional assessments of mental capacity (particularly where such assessments result in denials of legal capacity). Paragraphs 12 and 13 of the GC state as follows:

“12. Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing) and to exercise these rights and duties (legal agency). . . . Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors. ... Under Article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity... The concept of mental capacity is highly controversial in and of itself. It is not, as it is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity.

13. In most of the State party reports that the Committee has examined so far, the concepts of mental and legal capacity have been conflated so that where a person is considered to have impaired decision-making skills, often because of a cognitive or psychosocial disability, his or her legal capacity to make a particular decision is consequently removed. This is decided simply on the basis of the diagnosis of an impairment (status approach), or where a person makes a decision that is considered to have negative consequences (outcome approach), or where a person’s decision-making skills are considered to be deficient (functional approach). The functional approach attempts to assess mental capacity and deny legal capacity accordingly. (Often based on whether an individual can understand the nature and consequences of a decision and/or whether she/he can use or weigh the relevant information.) This functional approach is flawed for two key reasons. The first is that it is discriminatorily applied to people with disabilities. The second is that it presumes to be able to

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⁴ Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, Paragraph 23, UN Doc. No. CRPD/C/GC/1, adopted at the 11th Session (April 2014).
accurately assess the inner-workings of the human mind and to then deny a core human right – the right to equal recognition before the law – when an individual does not pass the assessment. In all these approaches, a person’s disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but rather requires that support be provided in the exercise of legal capacity.”

15. The aim of the GC in this area is to ensure that legal capacity is de-coupled from prejudicial perceptions of an individual’s ‘mental capacity.’ It seeks to ensure that regardless of an individual’s level of decision-making skills, she or he is still respected as a person before the law and a legal agent. If intervention in legal decision-making does occur, it must be based on factors that all individuals could be subject to, not merely people who have a cognitive disability or are perceived as lacking decision-making skills.

16. The GC also provides guidance for States on the development of support for the exercise of legal capacity. It is intentionally not over-prescriptive on this issue and does not provide a comprehensive list of examples of good practice. This was done in order to allow States to develop their own culturally and jurisdictionally specific practices.

Compatibility of the Mental Capacity Act 2005 and the CRPD

17. There is a growing consensus among academics,5 NGOs6 and even members of the judiciary7 that the MCA – and the deprivation of liberty safeguards (DoLS) – are not compatible with the CRPD. This view appears all the more likely in the wake of the CRPD Committee’s adoption of the General Comment on Article 12. In oral evidence to the House of Lords Select Committee on the MCA, the Ministry of Justice told the Committee that the government had initially received legal advice to the effect that the MCA was CRPD compliant, but since that time concerns had been raised and they were conducting a review of the compatibility of the MCA and the CRPD.8

Non-Discrimination

18. It is vital to understand the non-discrimination ethos of the CRPD to understand its position on legal capacity.9 The MCA couples a person’s ‘legal capacity’ (their legal agency) to their ‘mental capacity’

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through the functional test of capacity\textsuperscript{10} and the diagnostic threshold.\textsuperscript{11} The GC considers that functional approaches are flawed because they are ‘discriminatorily applied to people with disabilities’.\textsuperscript{12} The support model introduced by the CRPD is designed to remove this element of discrimination.\textsuperscript{13} A point made in the wider CRPD literature is that many people without disabilities might fail functional tests of capacity if they were actually subjected to them, but only people with disabilities are required to take them and experience the consequences of failing them.\textsuperscript{14} There is continuing debate regarding whether it would be possible to remedy this discrimination issue by removing the ‘diagnostic threshold’ of the MCA.\textsuperscript{15} Some argue that since the MCA also applies to people without disabilities, for example a person with concussion, it is not discriminatory\textsuperscript{16} – however such arguments do not take into account the possibility of indirect discrimination through the disproportionate application of the MCA to people with disabilities.

\textbf{The MCA as a Substituted Decision-Making Regime}

19. In the GC, the CRPD Committee has called upon States to abolish ‘substitute decision-making regimes and mechanisms that deny legal capacity which discriminate in purpose or effect against persons with disabilities’.\textsuperscript{17} It also defined what constitutes a ‘substituted decision-making regime’.\textsuperscript{18} The MCA meets all three elements of the definition and therefore can be deemed a ‘substitute decision-making regime.’ The MCA’s provision for ‘declarations of incapacity’\textsuperscript{19}, voiding a person’s past or future decisions in the relevant area, meet the first element of substitute decision-making: the removal of legal capacity. The second aspect of substituted decision-making, the existence of a substitute decision-maker that may be against the will of the person concerned, is also met because the MCA allows for the appointment of a deputy,\textsuperscript{20} potentially against the will of the person concerned. In addition, once a person is found to ‘lack capacity’ under the MCA, a substitute decision-maker is empowered to make a best interest decision.\textsuperscript{21}

\footnotesize
\begin{enumerate}
\item S3(1) MCA
\item S2(1) MCA
\item Paragraph 13, Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, Paragraph 23, UN Doc. No. CRPD/C/GC/1, adopted at the 11\textsuperscript{th} Session (April 2014).
\item In oral evidence to the House of Lords Select Committee, Professor Kirsty Keywood suggested this as being required by the CRPD: The Select Committee on the Mental Capacity Act 2005 (2013) \textit{Oral and written evidence – Volume 2 (L – W)}, House of Lords, UK Parliament. Q41. This solution would, of course, pose difficulties for advocates relying on s2(1) to limit the scope of ‘mental incapacity’ and ‘best interests’ decision making, in cases such as \textit{PC & Anor v City of York Council} [2013] EWCA Civ 478.
\item Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, Paragraph 46, UN Doc. No. CRPD/C/GC/1, adopted at the 11\textsuperscript{th} Session (April 2014).
\item Committee on the Rights of Persons with Disabilities, General Comment No. 1 – Article 12: Equal Recognition Before the Law, Paragraph 23, UN Doc. No. CRPD/C/GC/1, adopted at the 11\textsuperscript{th} Session (April 2014).
\item S15 MCA.
\item S16 MCA.
\item S 4 MCA.
\end{enumerate}
Where a person objects to an ‘informal’ decision-maker making substitute decisions under the ‘general defence’, this would also meet this second element, as informal decision-makers are empowered to make decisions whether or not the person wishes them to do so. Finally, the last element of a ‘substituted decision-making regime’ is met because s4 MCA allows for best interests decisions to be made on the basis of ‘objective’ criteria, rather than the person’s own will and preferences.

20. It is perhaps not fair to say that all decisions made under s4 MCA would violate the CRPD. There are examples of decisions which do strive to reflect the person’s will and preferences, and some argue that the Supreme Court’s ruling in *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 takes us closer to a CRPD compliant interpretation of ‘best interests’. However, there are also examples of decisions made under the MCA, which clearly do conflict with a person’s past or present wishes, and so which would fall afoul of this prohibition.

**Safeguards**

21. Since the passage of the Mental Capacity Bill, there have been concerns about whether the safeguards contained within the MCA are adequate, especially for decisions made informally under what became known as the ‘general defence’. These concerns continued to be expressed in evidence to the House of Lords Select Committee on the MCA. Bartlett and Sandland view the ‘absence of administrative safeguards against misuse’ of the MCA as potentially violating Article 12(4).

**Support**

22. The MCA requires that ‘A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success’. These provisions clearly have some consistency with the support paradigm of the CRPD, however as Senior Judge Lush has observed, ‘it can hardly be said that these constitute “a detailed and viable framework for supported decision-making in the exercise of legal capacity in accordance with the provisions of Art 12 of the convention”’ in contrast with other systems which make more explicit provision for supported decision making (discussed below).

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22 S5 MCA.
23 The ruling in *Westminster City Council v Sykes* [2014] EWHC B9 (COP) is a good example of this.
25 For example, *NHS v VT & Anor* [2013] EWHC B26 (Fam) and *Northamptonshire Healthcare NHS Foundation Trust & Anor v MI (Rev 1)* [2014] EWCOP 2.
27 House of Lords Select Committee on the Mental Capacity Act 2005 (2014) *Mental Capacity Act 2005: post-legislative scrutiny*, TSO: London. (Disclosure: this was a key concern in the evidence submitted by Professor Phil Fennell and Dr Lucy Series; Lucy Series contributed to this paper).
28 S1(3) MCA, and see also s3(2) MCA.
29 Bartlett and Sandland, (2013), see n9.
23. The MCA approach to support may not comply with the CRPD’s approach in four key respects. Under the CRPD, the goal of support is to help a person to exercise their legal capacity, rather than to pass a functional test of capacity; that is, support must be available regardless of ‘mental capacity’. The CRPD’s model of support is highly consensual: support cannot be imposed against a person’s will, and support ‘must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests’. The CRPD requires ‘Legal recognition of the support person(s) formally chosen by a person’ to ‘be available and accessible’; at present the MCA affords no means for a person to designate a chosen and trusted individual to be recognised by others as their supporter. Such a mechanism might be useful to address a difficulty highlighted by the House of Lords Select Committee on the MCA that people’s ‘natural’ supports, such as families and friends, are sometimes pushed aside by professionals and not included in supporting a person to make a decision. Finally, according to Article 12, decisions made with support are to be regarded as having been validly made by the person, regardless of how much support they have relied upon.

Other Elements of the CRPD

24. Decisions made under the MCA also potentially violate other elements of the CRPD, because several other articles incorporate requirements that a person is free to make a decision for themselves and that decisions should not be imposed upon them against their will.

25. Article 14 CRPD – the right to liberty and security of the person – presents a challenge to the MCA DoLS. Article 14 states that ‘the existence of a disability shall in no case justify a deprivation of liberty’. The United Nations Office of the High Commissioner on Human Rights (OHCHR) emphasises that during the negotiations of Article 14, efforts to specify that deprivation of liberty could not be justified ‘solely’ on grounds of disability were rejected, and so under the CRPD deprivation of liberty will be unlawful if it ‘is grounded in the combination between a mental or intellectual disability and other elements such as dangerousness, or care and treatment’. The OHCHR goes on to say that this does not mean that people with disabilities cannot be lawfully detained, ‘but that the legal grounds upon which restriction of liberty is determined must be de-linked from the disability and neutrally defined so as to apply to all persons on an equal basis.’

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31 GC paragraph 25(i).
32 GC paragraphs 17 and 25(g).
33 GC paragraph 25(b). Contrast with, for example, A Local Authority v TZ (No. 2) [2014] EWHC 973 (COP).
34 GC paragraph 25(d).
35 House of Lords Select Committee on the MCA (2014), n27.
36 GC paragraph 25(b) and 25(c). Contrast with the view taken in Verlander v Rahman [2012] EWHC 1026 (QB) that because Ms Verlander only made decisions ‘with the substantial assistance of her mother’, she lacked financial capacity as the ‘guiding person’ making decisions was her mother [94].
38 Paragraph 49
26. Bartlett argues that the DoLS – and the Mental Health Act 1983 - are not compatible with Article 14 CRPD, because disability does form part of the grounds for detention under both regimes.\(^{39}\) As Fennell and Khaliq point out, this gives rise to a conflict of laws between the CRPD and Article 5 of the European Convention on Human Rights (ECHR), the CRPD requiring that disability forms no part of the justification for a person’s detention, and ‘unsoundness of mind’ forming one permitted justification for deprivation of liberty under Article 5(1)(e) ECHR.\(^{40}\)

27. Several cases heard under the MCA have resulted in treatments being imposed on a person against their will, including forced feeding,\(^{41}\) sterilisation,\(^{42}\) and other medical interventions.\(^{43}\) These are likely to violate several other elements of the CRPD than Article 12. In its concluding observations on state reports, the Committee has repeatedly held that forced treatment in mental health services and non-consensual sterilisation violate Article 17 – the ‘right to respect for his or her physical and mental integrity on an equal basis with others’.\(^{44}\) Practices such as ‘continuous forcible medication’, enforced ‘correctional therapy’, chemical, physical and mechanical restraint, and seclusion, have been held to constitute inhuman and degrading treatment which contravene Article 15 CRPD.\(^{45}\) The CRPD does incorporate rights to health (Article 25) and habilitation and rehabilitation (Article 26), but these emphasise that services are voluntary and that medical treatment is based on informed consent.

28. Several Court of Protection cases have imposed measures on a person against their will which aim to promote ‘independent living’.\(^{46}\) Under Article 19 CRPD, ‘independent living’ is not a particular service model or a set of life skills which reduce reliance on others for support, but a right to choose one’s ‘place of residence and where and with whom they live on an equal basis with others’ and not to be ‘obliged to live in a particular living arrangement’. Requiring a person to live in ‘independent living’ settings against their will would violate Article 19 CRPD.

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\(^{41}\) Re E (Medical treatment: Anorexia) (Rev 1) [2012] EWHC 1639 (COP); A NHS Trust v Dr. A [2013] EWHC 2442 (COP)

\(^{42}\) A NHS Trust v Dr. A [2013] EWHC 2442 (COP)

\(^{43}\) e.g. Re AA [2012] EWHC 4378 (COP), NHS Trust v K & Ors [2012] EWHC 2922 (COP).

\(^{44}\) See the Committee’s concluding observations on Tunisia (CRPD/C/TUN/CO/1), Spain (CRPD/C/ESP/CO/1), Argentina (CRPD/C/ARG/CO/1) and Australia (CRPD/C/AUS/CO/1).

\(^{45}\) See the Committee’s concluding observations on Peru (CRPD/C/PER/CO/1), China (CRPD/C/CHN/CO/1) and Australia (CRPD/C/AUS/CO/1). See also Méndez, J. E. (2013) ‘Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment’, in 22nd session of the Human Rights Council, 4th March 2013, Geneva.

\(^{46}\) A Primary Care Trust v P [2009] EW Misc 10 (EWCOP); Northamptonshire Healthcare NHS Foundation Trust & Anor v MI (Rev 1) [2014] EWCOP 2.
Scottish capacity law and the CRPD

29. Scottish legal capacity provisions enjoy some significant similarities with the MCA, but also some significant differences. The Adults with Incapacity (Scotland) Act 2000 (AWIA) governs ‘interventions’ and the appointment of guardians for personal and property and affairs, and other mechanisms permit involuntary placement in care services. Like the MCA, the AWIA permits interventions and the appointment of guardians on the basis that an adult is ‘incapable’ — which is defined in a similar, although not identical, fashion to the ‘functional test’ under the MCA. The AWIA does not use a ‘best interests’ test, but it does permit interventions which would ‘benefit’ the adult, provided ‘such benefit cannot reasonably be achieved without the intervention’ and it is the least restrictive option consistent with the purpose of the intervention. The AWIA requires a similar consultation process to the ‘best interests’ test under the MCA.

30. In contrast with the MCA, far less has been written about the compatibility of Scottish legal capacity provisions with the CRPD. The Scottish Law Society has argued that Scottish incapacity laws not only comply with, but exceed, the requirements of Article 12 CRPD, but this argument is inconsistent with the interpretation of Article 12 contained in the GC. Because Scottish incapacity law does not confer such extensive ‘informal’ decision making powers as the MCA, it might be argued to contain more safeguards commensurate with Article 12(4) CRPD. Scotland also has stronger provision for advance statements, albeit non-binding, for mental health treatment than England and Wales. However, Scottish capacity law still permits decisions which could conflict with the person’s own ‘will and preferences’ on the basis of an assessment of mental capacity, and as such would not comply with the interpretation of Article 12 contained in the GC.

Good Practice in Support for the Exercise of Legal Capacity

31. Throughout the world there are a number of discrete laws, policies, pilot programs and research initiatives, which together indicate how the support model of Article 12 might appear in law, policy and practice. A range of innovative law reform activity has seen the development of statutory and non-

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48 s13ZA Social Work (Scotland) Act 1968 (as amended)
49 s1(6) AWIA
50 s1(2) AWIA
51 s1(3) AWIA
52 s1(4) AWIA, see also s1(5) AWIA
54 See Ward, A. (2014), n47
55 s275-6 Mental Health (Care and Treatment) (Scotland) Act 2003. The Scottish Government is also consulting on amendments which would strengthen the operation of advance statements: A Consultation on proposals for a Mental Health (Scotland) Bill, http://www.scotland.gov.uk/Publications/2013/12/1962
56 See Wallace, above n 8, 4. The Victorian Office of the Public Advocate is also undertaking a pilot supported decision-making program that will begin in 2014. For more information, see
statutory models of supported decision-making, including in adult guardianship law reform, personal advocacy, advance directives, and in a range of service-delivery pilot programs.

**Adult Guardianship Law Reform Activity in Canada**

32. Canadian adult guardianship law reform has included statutory measures to provide supported decision-making and other forms of support to exercise legal capacity. Similar legislative measures appear in Scandinavia, Japan and Australia, and are currently being developed further in the Republic of Ireland.

33. British Columbia’s *Representation Agreement Act 1996* provides for statutory supported decision-making in the form of the judicial appointment of ‘representatives’ chosen by the person receiving support. Under the Act, ‘representation agreements’ provide for a contractual agreement between two or more adults to formalise a support relationship. The relevant person can appoint a representative to help him or her make various decisions to do with personal, health and financial matters. This appointment can take place even where a person would not pass a mental capacity assessment, and s8 of the Act sets out more expansive criteria for validating the appointment, including where the person “demonstrates choices and preferences and can express feelings of approval or disapproval of others” and where the relationship “is characterized by trust.” A representative has statutory powers to gather information and a duty to assist the person by communicating his or her wishes to others. In certain circumstances, representatives may also be appointed to make substitute decisions using a ‘best interests’ standard, including if the person’s wishes are not known or in relation to healthcare decisions. While this latter substitute decision-making power means the legislation does not reach the ‘gold standard’ of Article 12 of the CRPD, as previously noted, the Act is generally considered as a progressive step toward CRPD-compliant legal capacity law. As with the MCA, representatives must endeavour to guide their support by the person’s will and preference, including his or her known beliefs and values.

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57 See generally, L Kerzner, ‘Paving the way to Full Realization of the CRPD’s Rights to Legal Capacity and Supported Decision-Making: A Canadian Perspective’ prepared for "In From the Margins: New Foundations for Personhood and Legal Capacity in the 21st Century" (Workshop), University of British Columbia (2011) [http://jennyhatchproject.net/sites/default/files/paving_the_way_for_crpd_canada.pdf](http://jennyhatchproject.net/sites/default/files/paving_the_way_for_crpd_canada.pdf) viewed 22 May 2014.


59 Assisted Decision-Making (Capacity) Bill 2013 (Republic of Ireland).

60 Representation Agreement Act BC 1996 c 405.

61 Representation Agreement Act BC 1996 c 405 s 7.

62 Ibid s 8(2)(b),(d).

63 Representation Agreement Act BC 1996 c 405 s 18.

64 Representation Agreement Act BC 1996 c 405 s 16.

65 See for example, Representation Agreement Act BC 1996 c 405 s 16(4)(b),(7).

66 Ibid 16(4)(a).
34. Another Canadian province, Prince Edward Island, saw the Supported Decision-Making and Adult Guardianship Act 1997 receive Royal Assent in 1997, but was never proclaimed in force, which provides for a ‘supported decision making agreement’ for persons over 18.67 Under the Act, a patient in Prince Edward Island, for example, would have the right to be assisted by an ‘associate’ when making health care decisions.68 In the Yukon territory, the Decision Making, Support and Protection to Adults Act69 is described by the British Columbia Law Institute Canadian Centre for Elder Law Studies as “...nearly a complete code on supported decision-making in the province.”70 Yukon’s supported decision-making legislation includes a form of ‘representative decision-making agreement’ and a less intensive form of ‘assisted decision-making arrangement.’71

35. These measures were intended to provide power to informal supporters of people with complex communication or decision-making support needs related to intellectual and cognitive disability (and nominally to persons with psychosocial disability).72 The laws aim to formalise supports that most people enjoy – such as advice from family, colleagues and professionals – and remind these supporters of their new role in supporting the decision of an equal citizen and a peer (rather than a minor).73

Swedish Personal Ombud

36. Swedish law provides for the judicial appointment of ‘Personligt ombud’ (PO) to assist a person to make legal decisions.74 The PO functions as a sort of legal mentor or personal ombudsman, and are often referred to as ‘assistants’ or ‘advocates’. The PO scheme is both social service and legal structure, and provides for a range of support relationships for people with disabilities and other disadvantaged people. These various formal supporters generally comprise trained social workers or lawyers who must be able to ‘argue effectively for the client’s rights in front of various authorities or in court,’ as required.75

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69 The Decision Making, Support and Protection to Adults Act S.Y. 2003, c. 21
71 Ibid.
72 There was also an express interest in protecting the rights of elder citizens who were increasingly falling under the provision of adult guardianship laws. Reform has taken place in the following jurisdictions: Quebec, Ontario, British Columbia, Manitoba, Prince Edward Island, and the Northwest Territories, and that have been discussed in Nova Scotia and Yukon. R Gordon, ‘The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making’ (2000) 23(1) International Journal of Law and Psychiatry 64.
73 Ibid.
37. The defining features of the PO model, according to a report by the Swedish National Board of Health and Welfare, are as follows:

“The client’s experienced needs and wishes are in focus, not the diagnosis and the treatment;
The work is based on the client’s health and his/her potential, rather than on symptoms, problems and limitations;
The client chooses the PO, not the other way round;
The client, and not the PO, sets the agenda and controls the process.”\footnote{76}

38. A useful snapshot of the work of POs is set out in the same report:

“After a stay in hospital, a client wanted to live in a flat of his own. Since this was the client’s wish, he was supported by the PO, while many other professionals involved with the client advised against it, saying that it would not work out. This in fact turned out to be the case: the client eventually moved into housing with special support and was very happy there. Professionals in the social services and psychiatric services thought that this was an unnecessary failure, while the PO’s view was that the reason why the client was so happy in the special housing was that he had been given the chance to live in his own flat.”\footnote{77}

39. The province of Skane, in particular has a well-developed personal ombud system for providing support to people with psycho-social disability. “PO Skane” allows the individual who may want support to direct the relationship. The relationship is developed gradually throughout time. The ombudsperson cannot act until the individual requests him or her to do so. Although the system established in Sweden is primarily funded by the Swedish government, the ombudspersons operate completely independently and are only accountable to the individual that they are supporting.\footnote{78}

40. The Office of the High Commissioner for Human Rights identified the PO scheme as an effective statutory mechanism for providing supported decision-making to persons with psychosocial disability, in line with the CRPD.\footnote{79} Elsewhere, Herr describes Sweden as ‘one of the most advanced countries in developing legal techniques to reinforce rather than disregard a person’s capacity for making choices.’\footnote{80}

41. As well as providing a good practice from a human rights perspective, the scheme reportedly has a fiscal benefit. The Swedish National Board of Health and Welfare report savings up to 17 times the cost of the service itself.\footnote{81} The saving is explained by a reduction in the number of crises and by the POs facilitative role in co-ordinating between services and highlighting weaknesses in service provision.

\footnote{77}{Ibid 14.}
\footnote{78}{PO-Skane, “Swedish User-Run Service with Personal Ombud for Psychiatric Patients”, http://www.po-skane.org/}
\footnote{81}{Swedish National Board of Health and Welfare, 23-24.}
**The Republic of Ireland – Current Law Reform Efforts**

42. The Republic of Ireland is in the process of developing its *Assisted Decision-Making (Capacity) Bill 2013*. The Bill is currently about to progress to the third major stage in its passage through Irish Parliament. One of the most important innovations of the Bill is that ‘best interests’ standards will be replaced with the will and preference of the person as a core guiding principle in all interventions under the Bill. However, the Bill in its current form does allow for courts to deprive individuals of legal capacity for certain decisions based on functional assessments of mental capacity.

43. Three categories of decision-making appear likely to emerge: assisted decision-making, co-decision-making and representative decision-making. The details of the role and responsibility in each category of support are likely to change as the Bill passes through parliament, though the general nature of each category is likely to remain as follows. Assisted decision-making agreements would see informal supporters being formalised as ‘assistants’ to the relevant person, helping to gather information and assist him or her to understand and communicate. Co-decision-making agreements would see the appointment, by the relevant person, of a ‘co-decision-maker’ where decisions would need to be jointly agreed upon—again, guided by the will and preference of the relevant person. Finally, where the court finds that despite the provision of support, and in the absence of less restrictive alternatives, an individual fails the functional assessment of mental capacity for a particular decision, ‘decision-making representatives’ will appointed by courts to make a decision on the relevant person’s behalf. However, importantly, decision-making representatives are required to act on the basis of the ‘will and preference’ of the relevant person, not on the basis of objective or perceived ‘best interests’. The Bill is likely to be enacted in 2015.

**Pilot Supported Decision-Making Project, South Australia**

44. The Office of the Public Advocate (OPA) of South Australia trialled a non-statutory supported decision-making program, which it described as a ‘process of setting up supported decision-making agreements, and supporting the participants with those agreements.’

82 26 participants with disabilities joined the pilot project and entered into supported decision-making agreements.

45. The aim was to create ‘an alternative to guardianship... for people who might otherwise be subject to guardianship if they cannot be seen to make decisions for themselves.’

83 The researchers also wanted to ‘test supported decision-making as an early intervention strategy for people not yet under guardianship’ which was aimed at preventing ‘problems occurring in the future, avoid[ing] the need for guardianship orders and facilitat[ing] age appropriate responses and skills in self determination.’

84 The pilot succeeded on both accounts, diverting people away from both welfare guardianship and administration orders,

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82 Ibid 5.
83 Ibid.
84 Ibid.
which are broadly similar to property and affairs deputyships under the *Mental Capacity Act 2005* (England and Wales).

46. An independent evaluation of the study detailed the project outcomes.85 Reported benefits include an increase in service providers’ appreciation of their clients’ capacity to act. There was also a reduction among participants in the number of Administration Orders (which provide for substitute decision-making in financial matters) where all who took part in the project successfully applied to have the administration orders lifted. Participants argued that they were able to use the support model to make their own decisions in all other areas of their lives including in financial matters. The South Australian Office of the Public Advocate has since developed a ‘population-based model of delivering supported decision-making’ and similar pilot projects are occurring in multiple states throughout Australia.

*Supported Decision-Making in Practice*

47. While supported decision-making is commonly criticised for being overly abstracted at the level of international law, the idea can be seen to have begun ‘on the ground’ in practical efforts to support people with disabilities to live self-directed lives. These practices have developed with people with disabilities, families, peer groups and professionals, often alongside the development of law and policy. The practical examples of supported decision-making listed above, which are only a small example of existing practices, can help to develop the ‘support model of legal capacity’ in line with Article 12. The increasing number of pilot programs, and evaluations of existing measures in law and policy, are helping to generate indicators, benchmarks, impact assessments, budgetary analysis and so on. These markers are also helping to uncover existing practices which could be conceived as ‘support to exercise legal capacity.’

*Addressing the ‘Hard Cases’ and Common Criticisms of Article 12 CRPD*

48. This final section of the article will consider some of the objections (and counter-arguments) to the UN CRPD approach to legal capacity.

*How does the paradigm of Article 12 respond to individuals who, after all efforts of support have been attempted, are not able to direct their own lives?*

49. Most people are quite happy to talk about providing support for people with disabilities to exercise legal capacity. They are less willing to accept that ALL people with disabilities should be provided support to exercise legal capacity. Many people initially think that support should or can only be provided to people who have well-developed communication skills where it is easy to see that they understand the relevant issues. However, Article 12 does not only apply to certain people with disabilities – it applies to all people with disabilities.

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50. People often refer to this issue as ‘the hard cases.’ This includes cases where: the individual is non-communicative or minimally communicative; where the individual is communicative but her or his will and preference is unclear or conflicting; where her or his will and preferences are clear but impracticable; and where there is concern that an individual is being unduly influenced by another individual. Providing solutions to these ‘hard cases’ is often the key to assisting people to understand what a system that is truly compliant with Article 12 would look like.

51. The simple answer to the issue of the ‘hard cases’ is that the support paradigm of Article 12 is asking that in these ‘hard cases’ the primary consideration is how to understand and realise the will and preference of the individual. It is merely saying that it is inappropriate to make decisions for people based on outside judgments of what the individual should want or what is in her or his ‘best interests.’

52. The more detailed answer is as follows. Where a decision needs to be made and an individual is non-communicative or minimally communicative, after significant attempts have been made to facilitate communication, an outside decision-maker can make a decision on her or his behalf in accordance with the ‘best interpretation’ of her or his will and preference, taking into account past expressed preferences, where available, knowledge gained from family and friends and any other evidence that is available.86 In this situation, the individual must be closely consulted to discover who she or he would like to appoint as a representative decision-maker. If she or he is communicating but not clearly expressing who she or he would like to make a decision on her or his behalf, then a decision-maker could be appointed, but again, could only make decisions that were in accordance with the best interpretation of her or his will and preference. This will rarely be an easy task, however ‘best interest’ determinations that are currently used are similarly difficult in these situations. Article 12 is merely shifting these difficult decisions from focusing on judgment existing outside the individual to the individual’s own will and preference.

53. Where an individual is communicative but is expressing conflicting wishes, after all efforts have been made to clarify and reconcile her will and preferences, an outside decision-maker can make a decision based on the best interpretation of her will and preference at that particular time. This may be one of the most difficult situations in which to apply Article 12. A commonly used example of conflicting will and preferences is that of anorexia. Many people with anorexia express a will to live, but a preference to not eat.87 In these cases, an outside decision-maker may be involved, but would still be restricted from making a decision that was contrary to the individual’s expressed will and preference. PEG feeding, for example, would only be allowed if the individual agreed to it. These situations will always be difficult – they are difficult under ‘best interests’ determinations and they will continue to be difficult under an approach that prioritises will and preference.

54. Where an individual’s will and preferences are clear but impracticable, the law should ask nothing more than it already asks. If an individual’s will and preference is an illegal action, no one can be forced to

86 General Comment No.1, Article 12: Equal Recognition Before the Law, Paragraph 18bis, UN Doc No. CRPD/C/GC/1, Committee on the Rights of Persons with Disabilities, 11th session (31 March –11 April 2014).

87 See, for example, Re E (Medical treatment: Anorexia) (Rev 1) [2012] EWCOP 1639 (15 June 2012).
support or realise that will and preference and the individual can be held responsible for the decision if the crime or illegal action is committed. This raises larger questions of the functioning of criminal justice systems. As it currently exists, people with cognitive disabilities are disproportionately represented in criminal justice systems. 88 This requires significant further study to explore how to remedy this problem while simultaneously respecting the autonomy of people with cognitive disabilities and their right to equal recognition before the law. If it is civil penalties that are at risk, the individual could potentially be held responsible for these. This then also begs an examination of the civil legal system, including contract law, civil responsibility, and others – however, there is not space in this newsletter to explore those areas.

55. Where there is a suspicion that an individual is being unduly influenced by another individual, Article 12 of CRPD directs that the law must treat people with disabilities the same as it does people without disabilities. For example, contract law provides for the invalidation of a contract where undue influence is found based on the nature of the relationship between the parties, not the existence of the label of disability. Where there is suspicion that a person with a disability may be experiencing undue influence, the law must only be allowed to intervene to the same extent as it would for a person without a disability. People without disabilities are permitted, under the law, to choose to live in settings that may seem unorthodox to outsiders. Some may even be in abusive households or under the oppressive control of a friend or family member. People with disabilities must be given the same freedom. However, there is an obligation to provide services that help reduce dependence and guarantee an alternative to abusive or dangerous settings; for example, supported living funding, affordable housing and supported employment.

56. This explanation of what to do in the ‘hard cases’ should NOT be equated to substitute decision-making systems that currently exist. There are clear distinctions, which are 1) using ‘will and preference’ as the guiding paradigm as opposed to ‘best interest,’ 2) not denying legal capacity to individuals with disabilities on a different basis, and 3) not imposing outside decision-makers against the will of the individual. 89

57. However, there are times in which a decision needs to be made and the relevant individual is not able to make a decision or needs assistance in making the decision. The foregoing explanation is meant to show that Article 12 can and does address these situations without the need for substituted decision-making. However, it is also important to stress that these solutions are ONLY intended to apply to the ‘hard cases’, and should not encroach into cases where an individual is expressing a will and preference – even where the will and preference of the individual is contrary to medical advice or to advice of mental health professionals. It should also not be used to impose an outside decision-maker on a person who is expressing an unpopular or unorthodox decision. The solutions proposed for these ‘hard cases’ only apply at the end of a process where there is a genuine inability to understand a person’s will and preference or

88 Research has found that 90% of the prison population have mental health issues. Kimmett Edgar and Dora Rickford, Too Little, Too Late: an independent review of unmet mental health need in prison, Page 7, Prison Reform Trust (2009). It is estimated that around 30% of people in the criminal justice system have learning difficulties or disabilities. “A joint inspection of the treatment of offenders with learning disabilities within the criminal justice system - phase 1 from arrest to sentence,” Page 2, Joint Inspection by HMI Probation, HMI Constabulary, HM Crown Prosecution Inspectorate and the Care Quality Commission (January 2014).

89 General Comment No.1, Article 12: Equal Recognition Before the Law, Paragraph 23, UN Doc No. CRPD/C/GC/1, Committee on the Rights of Persons with Disabilities, 11th session (31 March –11 April 2014).
where it is impossible to realise the person’s will and preferences without breaching some other aspect of the law.

58. Another issue that arises here is that, under the support model, the outside decision-maker may be asked to make, or support, a decision that she or he does not agree with. This can be extremely difficult, especially where the outside decision-maker also plays another role in the person’s life, such as a family member might do. Where this kind of dispute arises, there should be a process for the outside decision-maker to step down from the role of providing this kind of support to exercise legal capacity, if she or he so desires. The autonomy of the outside decision-maker must also be respected and she or he should not be forced to realise a decision of the individual that is morally repugnant to her or him or causes her or him great harm or distress. However, there must equally be another mechanism for providing a different outside decision-maker who will, in fact, realise the will and preference of the individual.

How does the paradigm of Article 12 deal with emergency situations?

59. Realising the right to legal capacity and the support paradigm of Article 12 requires that the will and preference of the individual is always paramount. However, this does not mean that vulnerable individuals who are having difficulty expressing their will and preference are going to be left by the wayside in emergency situations.

60. For example, in a situation in which an individual is displaying behaviours of serious self-harm, the support paradigm does not leave the individual to perish. Instead, it asks support people around the person to closely examine what is happening and to support the individual by taking actions that will facilitate her or his decision-making ability to a point at which she or he can clearly express her or his will and preferences. This could mean a variety of things, including but not limited to assisting the individual in stopping the self-harming behaviour and interacting with the individual in a caring and understanding manner and/or attempting to create an environment that the individual feels safe and comfortable in to allow her or him to be in an optimal decision-making scenario. Throughout any interaction, the goal remains of arriving at the will and preference of the individual. Further, according to the terms of the CRPD, any emergency interventions must adhere to the principle of non-discrimination by ensuring that criteria for crisis interventions do not discriminate on the basis of disability (for example, by using mental health diagnosis or mental capacity assessments).

61. The duty of care is likely to arise in these situations. While there is not space in this article for a full analysis of the duty of care in relation to Article 12, it will be important to re-examine practices that are currently justified as falling under a ‘duty of care,’ but may be unduly restricting the lives of people with disabilities.

62. The gravity of these issues highlights the importance of exerting great efforts to discover the will and preference of an individual and to help realise that will and preference to the greatest degree possible.
Conclusion

63. Both the AWIA and the MCA were ground-breaking pieces of legislation when they came into effect. Since that time, the global disability rights movement has gained significant voice and momentum. The CRPD is a product of that success. In their present form (for different reasons) neither the MCA nor the AWIA are compliant with the CRPD. However, their progressive elements and widespread use make them fertile ground for re-examination in the light of the CRPD as a whole, and Article 12 in particular. This is an opportunity for the United Kingdom to seize. The CRPD provides a framework and guidance within which the law can be reformed to truly respect the rights, will and preferences of people with disabilities. With the insight of people with disabilities, along with legal practitioners, mental health professionals, social workers, local authorities and others, there is the potential for the United Kingdom to be a global leader in realising the right to equal recognition before the law for people with disabilities.

Additional Resources

Scholarly Articles


Books and Book Chapters

- McSherry, Bernadette and Weller, Penelope, Re-thinking Rights Based Mental Health Laws (Hart 2010)

Legislative Materials

Position Papers

- International Disability Alliance, “Legal Opinion on Article 12 of the CRPD” (21 June 2008)

Lectures


Principles for Law Reform

- British Columbian law reform principles can be found in “How we can help,” a report published by the Community Coalition for the Implementation of Adult Guardianship Legislation (1992)
- Irish law reform principles can be found in the document “Essential Principles: Irish Legal Capacity Law” written by Amnesty Ireland and the Centre for Disability Law and Policy, NUI Galway in coalition with 15 organisations in Ireland (2012)

Supported Decision-Making Information

- NIDUS Website (British Columbia), ‘Nidus’ is the not-for-profit, charitable organisation that helps register and provide materials for the representative agreements available in British Columbia. http://www.nidus.ca/

Blog

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