

Support for the Exercise of Legal Capacity



EssexAutonomyProject

EAP Three Jurisdictions Project

Briefing Document

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1. Introduction

The purpose of this briefing document is to generate discussion, within the context of Article 12 UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the UN Committee on the Rights of Persons with Disabilities' (the Committee) General Comment No 1 (GC1)¹, on how persons with disabilities can be supported to exercise their legal capacity. It is not an exhaustive review of literature, legislation, practice and policy but provides an indication of some of the most recent thinking and continuing or emerging issues in the area.

'Legal capacity' has been described in a number of ways. It has, for instance, been described as "a person's power or possibility to act within the framework of the legal system"² and as comprising the two elements of 'legal standing' (being regarded as a person before the law) and 'legal agency' (the active exercise of the rights and duties that stem from being recognised as having legal standing).³ This definition is also that adopted by GC1.⁴ In short, legal capacity is the legal ability to bear and exercise rights.⁵

1.1. Articles 12(3) and 12(4) UNCRPD

Article 12(3) requires that States Parties provide access by persons with disabilities to support in order to exercise their legal capacity:

'States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.'

Article 12(4) then stipulates that safeguards must be in place to ensure that any such support arrangements:

'... respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.'

¹ UN Committee on the Rights of Persons with Disabilities, General Comment No 1 (2014) *Article 12: Equal Recognition before the Law*, CRPD/C/GC/1, adopted 11 April 2014.

² Council of Europe Commissioner for Human Rights, *The Right of People with Disabilities to Live Independently and Be included in the Community*, CommDH/IssuePaper (2012) 3, 12 March 2012, p 7. Available online: <https://wcd.coe.int/ViewDoc.jsp?id=1917847>

³ B McSherry, (1) 'Legal Capacity under the Convention on the Rights of Persons with Disabilities' (2012) 20 *Journal of Law and Medicine* 22-27; and (2) 'Decision-Making, Legal Capacity and Neuroscience: Implications for Mental Health Laws', (2015) 4 *Laws* 125-138, 127.

⁴ UN Committee on the Rights of Persons with Disabilities, General Comment No 1 (2014) *Article 12: Equal Recognition before the Law*, CRPD/C/GC/1, adopted 11 April 2014, para 13.

⁵ R Frimston, A Ruck Keene, C Van Overdijk and A D Ward, *The International Protection of Adults*, Oxford, 2015, para 1.09.

Articles 12(3) and (4) UNCRPD provide only general direction for support in exercise of legal capacity. GC1 adds interpretative substance in terms of giving broad examples of types of support and an interpretation of the environment in which such support must operate.

1.2. GC1 and types of support in the exercise of legal capacity

GC1 emphasises the potential range of support available in the exercise of legal capacity, which ‘encompasses both informal and formal support arrangements, of varying types and intensity’⁶. This can, for example, include⁷ one or more trusted persons, peer support and advocacy (including self-advocacy). It can also involve assistance with communication. This could be in the form of provision of information in an understandable format, professional sign language interpretation and the development and recognition of diverse, non-conventional methods of communication (especially for those who use non-verbal forms of communication to express their will and preferences).

Advance planning is also mentioned as a possible means of support:

‘the ability to plan in advance is an important form of support, whereby they can state their will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others.’⁸

The opportunity to plan in advance must be provided on an equal basis with others and without discrimination. Moreover, if the person so wishes, support should be provided to a person to complete an advance planning process. The point at which an advance directive enters into effect must be decided by the person and should not be based on an assessment that they lack mental capacity.

In a wider context, GC1 also recognises communities and the support that can be gained from these⁹. Amongst other things, it additionally reminds us that support for the exercise of legal capacity is required in judicial, administrative and other legal proceedings. This could include recognition of diverse communication methods, the use of video testimony, in certain situations, procedural accommodation, providing professional sign language interpretation and other methods of assistance¹⁰.

1.2.1. GC1 requirements for supported decision-making

Paragraph 29 of GC1 stipulates various requirements of ‘supported decision-making’. It is significant that the term ‘supported decision-making’ is used in this juncture, as opposed to ‘support in the exercise of legal capacity’ referred to in Article 12(3) UNCRPD, and this will be returned to later in this paper.

⁶ GC1, para 17. This corresponds with, and reinforces, the requirement for respect for diversity identified in Article 3(b) UNCRPD and GC1, para 18.

⁷ GC1, para 17.

⁸ GC1, para 17.

⁹ GC1, para 45.

¹⁰ GC1, para 39.

Again, reiterating that a supported decision-making regime is multi-faceted, paragraph 29 once more stresses that it must give primacy to a person's will and preferences and respect human rights norms¹¹, with no hierarchy of rights being envisaged¹², and that there must be protection from "undue influence" in any supported decision-making arrangements¹³. At the same time, supported decision-making should not, however, over-regulate the lives of persons with disabilities. It also sets out a list of key provisions that should be incorporated into the substance and provision of supported decision-making to ensure Article 12 compliance as follows:

- (a) Supported decision-making must be available to all. A person's level of support needs, especially where these are high, should not be a barrier to obtaining support in decision-making;
- (b) All forms of support in the exercise of legal capacity, including more intensive forms of 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;
- (c) A person's mode of communication must not be a barrier to obtaining support in decision-making, even where this communication is non-conventional, or understood by very few people;
- (d) Legal recognition of the support person(s) formally chosen by a person must be available and accessible, and States have an obligation to facilitate the creation of support, particularly for people who are isolated and may not have access to naturally occurring support in the community. This must include a mechanism for third parties to verify the identity of a support person as well as a mechanism for third parties to challenge the action of a support person if they believe that the support person is not acting in accordance with the will and preferences of the person concerned;
- (e) In order to comply with the requirement, set out in article 12, paragraph 3, of the Convention, for States parties to take measures to "provide access" to the support required, States parties must ensure that support is available at nominal or no cost to persons with disabilities and that lack of financial resources is not a barrier to accessing support in the exercise of legal capacity;
- (f) Support in decision-making must not be used as justification for limiting other fundamental rights of persons with disabilities, especially the right to vote, the right to marry, or establish a civil partnership, and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty;

¹¹ See also E Flynn and A Arstein-Kerslake, 'The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?' (2014) 32 *Berkeley Journal of International Law* 134, 134.

¹² 'including those related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where to live, etc.) and rights related to freedom from abuse and ill-treatment (right to life, right to physical integrity, etc.).' GC1, para. 29.

¹³ GC1, para 22. See also W Martin, S Michalowski and C Caughey, Briefing Paper: *Safeguards against Undue Influence and Conflicts of Interest*, Essex Autonomy Project Three Jurisdictions Project, Edinburgh Roundtable 2 (December 2015).

- (g) The person must have the right to refuse support and terminate or change the support relationship at any time;
- (h) Safeguards must be set up for all processes relating to legal capacity and support in exercising legal capacity. The goal of safeguards is to ensure that the person's will and preferences are respected.
- (i) The provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity.'

Whilst emphasising that the seeking and acceptance of support is voluntary on the part of the person with disabilities¹⁴, GC1 also makes it clear that one of the objectives of support in the exercise of legal capacity is that of confidence and skills building so that less support is required, if desired, to exercise legal capacity in the future¹⁵.

Importantly, GC1 distinguishes the right to reasonable accommodation to exercise legal capacity from the right to support to exercise legal capacity. CRPD Art. 2 defines reasonable accommodation so as to limit the state obligation to those forms of accommodation which do not impose a disproportionate or undue burden. According to GC1, however, this limitation does not apply in the case of support for the exercise of legal capacity.¹⁶ On this interpretation of the Convention, considerations regarding resources can have no place in decisions concerning the level of support in the exercise of legal capacity.

1.2.2. Key GC1 requirements summarised

Going forward, several key requirements of Article 12(3) UNCRPD, as interpreted and augmented by GC1, for support in the exercise of legal capacity, or supported decision-making, can be discerned and summarised as follows:

1. Such support must respect the rights, will and preferences of the disabled person (note also that GC1 states that 'primacy' must be given to these and decisions must not be made by others based on objective 'best interests' assessments) and there must be safeguards present that ensure this.
2. Seeking and accepting such support is entirely in the discretion of the person with disability.
3. Support must be diverse and can take many forms and must be available to all on an equal basis.
4. Access to support must not be dependent on assessments of mental capacity.

¹⁴ This is alluded to in several places throughout GC1 but in particular in paragraph 19.

¹⁵ GC1, para 24.

¹⁶ *'The right to reasonable accommodation in the exercise of legal capacity is separate from, and complementary to, the right to support in the exercise of legal capacity. States parties are required to make any necessary modifications or adjustments to allow persons with disabilities to exercise their legal capacity, unless it is a disproportionate or undue burden. Such modifications or adjustments may include, but are not limited to, access to essential buildings such as courts, banks, social benefit offices and voting venues; accessible information regarding decisions which have legal effect; and personal assistance. The right to support in the exercise of legal capacity shall **not be limited** by the claim of disproportionate or undue burden. The State has an **absolute obligation** to provide access to support in the exercise of legal capacity.'* (GC1, para 34; emphasis added)

5. Such support must never amount to substitute decision-making and must take place outside substitute decision-making regimes¹⁷. GC1 is explicit here: ‘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.’¹⁸

and

‘...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.’¹⁹

Moreover, states must play an active role in the provision of access to support for the exercise of legal capacity²⁰ which requires immediate, and not progressive, implementation²¹.

However, several questions remain fully or partially unanswered in the context of identifying and providing support for the exercise of legal capacity, some of which are listed in Section 2 below. These warrant further consideration. Summaries of examples of types of supported decision-making from various jurisdictions are provided in Section 3 to assist with such deliberations²².

2. Issues Requiring Further Consideration

2.1. Definitional Issues

The arguments in favour of supported decision-making are well-rehearsed. Davidson *et al* categorise these into three main groups of arguments – rights-based, effectiveness and pragmatic arguments²³. Rights-based arguments focus on the protection of autonomy and the universal nature of personhood. Effectiveness arguments highlight the benefit to individuals, families and society. Pragmatic arguments look to procedural justice and the fact that individuals are more likely to be happy with outcomes where opportunities to express their views are provided. Added to this are arguments that supported decision-making processes are less isolating²⁴, that they increase independence and enable community integration²⁵.

¹⁷ GC1, paras 17, 26, 28 and 42.

¹⁸ GC1, para 17.

¹⁹ GC1, para 28.

²⁰ GC1, paras 29, 50(b) and (c), 51 and 52.

²¹ GC1, para 30.

²² This is not to say, however, that other formal and informal forms of supported decision-making exist. Moreover, all or most of the examples provided currently exist in the context of mental capacity assessments being the means by which support is obtained and operate within substitute decision-making regimes.

²³ G Davidson *et al* ‘Supported decision-making: A review of the international literature’ (2015) 38 *International Journal of Law and Psychiatry* 61, 62.

²⁴ L Salzman, ‘Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act’ (2010) 81 *University of Colorado Law Review* 157, 161.

However, notwithstanding this, there is a lack of terminological clarity in the literature and generally about the meaning of supported decision-making²⁶. In a 2014 review, Browning et al distinguished several distinct ways in which the concept has been used.²⁷ In the broader sense, the term is used to refer to any process whereby “one person gives another person as much support as they need to be involved in the decisions that are important to them.”²⁸ Such support might be provided to an individual to enable them to make a decision for themselves, or it might be provided in order to help an individual express their will and preference in the context of substitute decision-making. In the narrower sense, the term has been used to designate “an alternative to substitute decision-making, and a system intended to replace guardianship.”²⁹

The distinction between support *with* decision making and supported decision-making has also been highlighted, with concern expressed that the term ‘support *with* decision-making’ only denotes assisting with decision-making and not enabling such decision-making to be given legal recognition and effect³⁰. Indeed, Gooding notes that the obligation on states in Article 12(3) UNCRPD is a broad obligation which includes advocacy, accessible documents etc. Supported decision-making, on the other hand, ‘refers to a decision made by a person, on his or her own behalf, with support from others to exercise legal capacity.’³¹ In Gooding’s opinion, ‘a supported decision-making regime includes *supported decision-making*, support *with* decision-making and broader *support to exercise legal capacity*, across a range of law, policy and practice.’³²

This still leaves open, however, the additional question of who exactly should provide the support in each support situation. Article 12 UNCRPD and GC1 make it clear that the state must ensure that support is provided for the exercise of legal capacity, but it is by no means clear who the provider of such support will be. It might be easier to identify those responsible for actually giving the support in formally recognised support arrangements where the state can be held directly responsible. It is much less easy to discern where there are informal support arrangements and the state has little or no direct involvement.³³

²⁵ J M Jameson ‘Guardianship and the Potential of Supported Decision Making with Individuals with Disabilities’ (2015) 40(1) *Research and Practice for Persons with Severe Disabilities* 36.

²⁶ R D Dinerstein ‘Implementing Legal Capacity under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making’ (2012) 19 *Human Rights Brief* 8-12; M Browning et al ‘Supported Decision-Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice’ (2014) *Research and Practice in Intellectual and Developmental Disabilities* 34, 36-37; P Gooding, ‘Navigating the ‘Flashing Amber Lights’ of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns’ (2015) 15 *Human Rights Law Review* 45, 50-52.

²⁷ Browning et al, 36-37.

²⁸ ACT Disability, Aged and Carer Advocacy Service 2013.

²⁹ Browning et al, 37.

³⁰ Browning et al, 41.

³¹ Gooding, 50-52.

³² Gooding, 52; P Gooding, ‘Supported Decision-Making – A Rights Based Disability Concept and It’s Implications for Mental Health Law’ (2013) 20(3) *Psychiatry, Psychology and Law* 437, 445.

³³ L Series, ‘Relationships, autonomy and legal capacity: Mental capacity and support paradigms’ (2015) 40 *International Journal of Law and Psychiatry* 80, 85.

2.2. How should the effectiveness of supported decision-making be assessed?

A second set of questions concern the empirical evidence needed to inform any move towards supported decision-making³⁴. Whilst there have been some small-scale evaluations indicating that certain type support have yielded positive results³⁵ more detailed published research is still awaited. Some have raised the question of whether supported decision-making mechanisms can in fact achieve the objectives envisaged by Article 12(3) UNCRPD and GC1³⁶. Indeed, in light of this, should we therefore be cautious about the extent to which we adopt supported decision-making?³⁷ There are many forms of purported supported decision-making arrangements throughout various jurisdictions but what should we be measuring in order to gauge actual effectiveness? Is it increased understanding and respect for the rights of all citizens which thus enable better decisions? Is it from the more procedural standpoint that when people are given more opportunity to express their views they are less likely to feel coerced and dissatisfied with a decision³⁸? In either case, how do we assess this?

It is also important to be clear about exactly what the effect that particular support is intended to have. For example, it is actually going to result in the greater exercise of legal capacity or is it going to result in greater participation only that falls short of achieving full autonomy?³⁹ We must guard against ‘conceptual dishonesty’⁴⁰.

It is additionally pertinent to consider, in the context of effectiveness of support in the exercise of legal capacity, the extent to which this must be reflected in legislation.

2.3. Respect for rights, will and preferences

As previously stated, Article 12(4) UNCRPD requires states parties to adopt safeguards that, inter alia, ensure that support arrangements respect the person’s rights, will and preference.

³⁴ N Kohn *et al* ‘Supported Decision-Making – A Viable Alternative to Guardianship?’ (2013) 117 *Penn State Law Review* 1111; N Kohn and J Blumenthal, ‘A critical assessment of supported decision-making for persons aging with intellectual disabilities’ (2014) 7 *Disability and Health Journal* S40, S41.

³⁵ See, for example, M Wallace, *Evaluation of the Supported Decision-Making Project*, South Australian Office of the Public Advocate, 2012 (involving individuals with intellectual disabilities, brain injuries and neurological conditions choosing a trusted person to support them and to make ‘support agreements’) and T Engman *et al*, *A New Profession is Born – Personligt ombud, PO, Socialstyrelsen Fhebe Hjälm*, 23, 2008, and I Nilsson, *Det lönar sig – ekonomiska effekter av verksamheter med personligt ombud* Welfare and the County Administrative Board of Skåne County, Stockholm, 2006 (both of which relate to the Public Ombudsman scheme in Skåne, Sweden), all of which are referred to in Series, 85-85.

³⁶ Kohn *et al*, 1128; T Carney, ‘Clarifying, Operationalising and Evaluating Supported Decision Making Models’ (2014) *Research and Practice in Intellectual and Developmental Disabilities* 46; Browning *et al*, 36-37.

³⁷ See Carney, ‘Supported Decision-Making for People with Cognitive Impairments: An Australian Perspective?’ (2015) 4 *Laws* 37, 41. See also S-N Then, ‘Evolution and Innovation in Guardianship Laws: Assisted Decision-Making’ (2013) 35 *Sydney Law Review* 133, 135

³⁸ Davidson *et al*, 62.

³⁹ Browning *et al*, 37.

⁴⁰ Then, 157.

GC1 interprets this as a requirement that supported decision-making regimes ‘*give primacy* to a person’s will and preferences and respect human rights norms.’⁴¹[emphasis added] and there is no place for objective best-interests assessments. Moreover, the support paradigm allows for the entire context of an individual’s life to be taken into account rather simply a snapshot of that person based on their information⁴². It is thus inherently linked to the personhood conception of legal capacity which allows for meaningful participation in society⁴³.

However, achievement of respect for an individual’s rights, will and preference might arguably not be as simple as it would first appear. Under international human rights treaties, the state is regarded as the primary guardian of our rights. What happens therefore when a person’s will and/or preference is inconsistent with other UNCRPD provisions, for instance the obligation for states parties to take measures to ensure the effective enjoyment of the right to life (Article 10, UNCRPD), and the obligation to take measures to ensure the protection and safety of persons with disabilities in situations of risk (Article 11, UNCRPD)⁴⁴? The impossibility of respecting both a person’s will and preferences where these stand in opposition to each other has already been noted⁴⁵. Similarly, there are various ways of defining wishes and it may not even be clear to the individual what their will or wish is. Indeed, for some individuals it is the decision-making process that is most important, rather than the final outcome⁴⁶. Moreover, as GC1 acknowledges, some people may prefer not to engage in supported decision-making processes and should not be forced to do so⁴⁷.

Finally, whilst there is an insistence that the will and preference of the individual should direct the decision-making, it has also been acknowledged that there will be circumstances in which this may not be possible. Such ‘hard case’ situations will be considered in the following section.

2.4. ‘Hard’ cases

‘Hard cases’ are often highlighted as barriers to the effective operation of supported decision-making. These include, for instance, situations involving self-harming or suicidal tendencies, people in comas, people who are otherwise unable to communicate in any apparently meaningful sense.

Without doubt, these situations provide serious challenges to deducing, understanding or giving effect to will and preferences. It could, of course, be asserted that making decisions ‘for’ people in such situations recognises the reality that it may not always be possible to determine or interpret will and preferences in every circumstance. GC1 states that ‘Best

⁴¹GC1, para.29

⁴²Series, 83.

⁴³Flynn and Arstein-Kerslake, 136.

⁴⁴Essex Autonomy Project (2014), 38-40; J Stavert, ‘The Exercise of Legal Capacity, Supported Decision-Making and Scotland’s Mental Health and Incapacity Legislation: Working with CRPD Challenges’, 4 *Laws* 296, 300.

⁴⁵Essex Autonomy Project (2014), 41-42

⁴⁶Kohn *et al*, 1140-1141.

⁴⁷G Davidson *et al*, 3; T Carney, ‘Participation and service access rights for people with intellectual disability: A role for law?’ (2013) 38(1) *Journal of Intellectual and Developmental Disability* 5962.

interpretation of will and preferences’ should be employed in situations ‘where, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual’.⁴⁸ Flynn and Arstein-Kerslake suggest that in such circumstances the person making the decision should ‘do so in a way which attempts to draw out the imagined will and preferences of the person.’⁴⁹ However, whether these ‘facilitated decisions’ can be regarded as ‘100% support’ in which the individual is deemed to be exercising their legal capacity is certainly not unanimously accepted⁵⁰.

2.4.1. Unconscious persons

In addressing a situation involving a person in a coma or apparently beyond meaningful communication, it has been suggested that the ‘best interpretation of will and preferences’ should be based on the ‘perceived wishes’ of the person⁵¹ and that support persons should be directed to look for ‘indications’ of will and preferences by speaking to those who know the individual, considering the person’s values and beliefs, and taking into consideration any past expressions that the person has made which are relevant⁵². Indeed, it has been suggested that deeply held beliefs that some people are beyond communication is possibly the greatest obstacle to full implementation of Article 12 UNCRPD⁵³.

However, it may be that the ‘best interpretation’ approach does not lend itself to some situations⁵⁴. It has been suggested that GC1 compatibility can be achieved by states setting boundaries as the extent of use of the best interpretation approach with such boundaries giving due consideration to rights, will and preference⁵⁵.

2.4.2. Situations of risk

The dignity of risk is a common theme in the literature with commentators noting that individuals with disabilities are often denied the right to take risks.⁵⁶ Denial of the ability to take risks may negatively impact on person’s sense of self.⁵⁷ However, a particular challenge

⁴⁸ General Comment para.21

⁴⁹ E Flynn & A Arstein-Kerslake, ‘Legislating personhood: realising the right to support in exercising legal capacity’ (2014) 10(1) *International Journal of the Law in Context* 81, 94.

⁵⁰ Series, 7; G Quinn, ‘Concept Paper – Personhood and Legal Capacity – Perspectives on the Paradigm Shift of Article 12 CRPD’ HPOD Conference Harvard University 20 February 2010.; K Booth-Glen, ‘Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond’ (2012) 44 *Columbia Human Rights Law Review* 93, 165-167

⁵¹ Gooding, 54.

⁵² Flynn and Arstein-Kerslake, 141-142.

⁵³ K Booth-Glen, 165-167.

⁵⁴ Gooding (2015), 54.

⁵⁵ Gooding (2015), 55.

⁵⁶ Gooding (2012), 435-436.

⁵⁷ A Dhanda, ‘Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar of the Future?’ (2007) 34(2) *Syracuse Journal of International Law and Commerce* 429, 436; F Morrissey, ‘The

for the supported decision-making paradigm presents itself, along with accompanying moral dilemmas, where a person rejects support and/or intimates a wish to place themselves in a situation of danger, exploitation, abuse or undue influence. Whilst some commentators have argued that support with decision-making is possible in such situations, provided it is appropriately pitched⁵⁸ - and, indeed, Flynn and Arstein-Kerslake also suggest that ‘a verbal expression in one instance may not necessarily represent the true will and preferences of an individual.’⁵⁹ - the idea that support can always be sufficient in crisis situations has been met with a certain amount of scepticism by others who consider that supported decision-making does have its limits⁶⁰.

2.5. Supported decision-making with and without substitute decision-making

As we have seen, GC1 expressly requires that supported decision-making replace regimes of substituted decision-making. However current experiments with supported decision-making in jurisdictions around the world typically seek to develop frameworks of support within an overall legal framework that permits substitute decision-making, even if only as a last resort. (For a survey of existing systems of supported decision-making, see section 3, below.) Moreover, the insistence upon the abolition of substitute decision-making is nowhere explicit in the Convention itself, and CRPD Art 12(3) and 12(4) can be interpreted as permitting the development of supported decision-making alongside substitute decision-making.

One of the key questions facing the three jurisdictions of the UK is therefore about where best to “locate” mechanisms of support. Two options (or rather: families of options) seem to be available.

The first option, which we might describe as “the GC1 option,” treats supported decision-making as the master-principle for all decisions pertaining to persons with disabilities. On this approach, the task is to devise legal and institutional mechanisms that can sit alongside informal networks to ensure that, in all matters, all persons with disabilities have all the support they need to realise their own will and preference in a matter (subject to the obvious constraints established by the criminal law). Paternalistic protective measures, substitute decision-making and the best-interests principle are therefore replaced by the principle of support.

An alternate approach would be to allow that there may be a variety of legally sanctioned mechanisms whereby decisions are made by or for persons with disabilities, where these might include certain forms of substitute decision-making. The task on this approach is then to embed support as integral to each of these mechanisms. In some cases support is provided to help the person exercise their own decision-making capacity; in other cases support is

United Nations Convention on the Rights of Persons with Disabilities: A New Approach to Decision-Making in Mental Health Law’ (2012) 19 *European Journal of Health Law* 423, 428.

⁵⁸ Gooding (2012), 436; Flynn and Arstein-Kerslake ‘Legislating Personhood’ 98.

⁵⁹ Flynn and Arstein-Kerslake ‘Legislating Personhood’, 98-99.

⁶⁰ K Del Villar, ‘Should Supported Decision-Making Replace Substituted Decision-Making? The Convention on the Rights of Persons with Disabilities and Coercive Treatment under Queensland’s Mental Health Act 2000’ (2015) 4 *Laws* 173, 193; G Richardson, ‘Mental capacity in the shadow of suicide: what can the law do?’ (2013) 9(1) *International Journal of the Law in Context* 87, 93 and 96.

provided to ensure (for example) that the person's will and preferences are identified and articulated in the process of making decisions that the disabled person is unable to make.

2.6. When does supported decision-making become appropriate?

As noted above, GC1 directs that the provision of support to exercise legal capacity should not be dependent on assessments of legal capacity⁶¹. This, however, raises the important question of at what point it is necessary, and appropriate, to provide such support⁶².

Bach and Kerzner have suggested a 'functional assessment' of decision-making capacity to determine which decision-making status a person would come under. Such an assessment of decision-making capability would be required 'to deal with situations where there is reasonable question as to whether a person has the capability to understand and appreciate, even with assistance, the nature and consequences of a decision; or if a person meets the minimum threshold for supported decision making.'⁶³ In this connection, 'fair and just arrangements' should be 'in place to determine the nature of a person's decision-making abilities and their particular needs for decision-making supports and accommodations.'⁶⁴ Such determinations should not occur purely because an individual is presumed to have a disability and should only be conducted in order to assess the type of support that is required⁶⁵. This proposal has, however, been challenged by Flynn and Arstein-Kerslake on the basis that Article 12 UNCRPD allows for no 'functional' assessment of decision-making capability and leaves it to the discretion of the individual as to the level of support they require⁶⁶.

3. Examples of Supported Decision-Making

3.1. The United Kingdom

3.1.1. Scotland

Whilst the Adults with Incapacity (Scotland) Act 2000 (AWIA) regulates situations following an assessment that an adult is 'incapable'⁶⁷ it does recognize advance planning in terms of powers of attorney that allow any individual with capacity to put in place arrangements for the organisation of their financial (continuing) and/or welfare affairs by appointing an individual or organization to act on their behalf.

⁶¹ GC1, para 29(i).

⁶² Richardson, 95.

⁶³ M Bach and L Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity*, Law Commission of Ontario, 2010, 98.

⁶⁴ Bach and Kerzner, 25.

⁶⁵ Bach and Kerzner, 25.

⁶⁶ Flynn and Arstein-Kerslake, 'Legislating Personhood', 89.

⁶⁷ As defined in s 1(6), AWIA.

The AWIA stipulates that certain conditions must be fulfilled for the power to be valid⁶⁸ - largely obligating solicitors acting for granters to be satisfied that the granting of the power is the result of an autonomous decision⁶⁹ – and there are virtually no limitations placed on the choice of attorney or the powers conferred. Those few limitations that are imposed suggest the objective of protection of the granter’s autonomy. For example, a welfare attorney may not place the granter in hospital for treatment for mental disorder against their will, consent to medical treatment excluded from the scope of the Act’s general power to treat⁷⁰, request that the granter’s body or body parts be used after death for anatomical/post-mortem examination or use of the granters’ body parts, tissue or organs during their life. The Act’s Code of Practice⁷¹ also encourages the person granting the power to discuss “feelings and wishes regarding the exercise of the powers”. Moreover, the Code⁷² recommends that detailed discussions between the granter and the attorney take place so as to ensure the attorney has an in-depth knowledge of the granter’s likes, dislikes and values.

Continuing powers of attorney may become operational at any time whereas welfare attorneys’ powers only become effective once the granter has lost capacity. However, the granter may determine in the document the extent of an attorney’s powers and, in the case of welfare attorneys or continuing attorneys that are to come into effect upon incapacity, how incapacity will be determined⁷³.

Attorneys are required under the Act to exercise their powers in accordance with the Act’s underlying principles⁷⁴. Such principles include the need to take into account ‘the present and past wishes and feelings of the adult so far as they can be ascertained by any means of communication, whether human or by mechanical aid (whether of an interpretative nature or otherwise) appropriate to the adult’⁷⁵. Whilst the Act does not give specific primacy to such wishes and feelings it does make it clear that they form an integral part of the equation. However, empirical research would be required to ascertain the extent to which this principle is actually implemented.

It is worth mentioning, although it is not included as a general principle, that the AWIA also directs⁷⁶ that anyone responsible for implementing an intervention authorised under it must encourage the exercise and development of skills of the adult where reasonable and practical

⁶⁸ AWIA, ss15 and 16.

⁶⁹ Sections 15(3)(c)(iii) (continuing powers of attorney: property or financial affairs) and 16(3)(c)(iii) (welfare powers of attorney) both state that the solicitor must satisfy themselves that they have ‘...no reason to believe that the granter is acting under undue influence or that any other factor vitiates the granting of the power’. This is further reinforced by the Law Society of Scotland’s Vulnerable Clients (paras 13-16) and Continuing and Welfare Powers of Attorney (paras 11 and 12) guidances published in 2013.

⁷⁰ AWIA, s47.

⁷¹ Para 2.18.

⁷² Para 2.19

⁷³ AWIA,ss15(3)(ba) and 16(3)(ba).

⁷⁴ AWIA, s1.

⁷⁵ AWIA, s 1(4)(a).

⁷⁶ AWIA, s 1(5).

to do so. This been noted as “surely one of the most important statements of ethos underlying the [2000] Act”⁷⁷.

Advance statements or directives are not formally recognised under the AWIA⁷⁸ and in Scotland there is an absence of relevant case law on these. However, it seems likely that the English approach will be followed in that advance refusals regarding treatment relating to physical health will be upheld although specific treatment preferences will not⁷⁹.

Finally, whilst again not formally recognised under the AWIA, independent advocacy is available across Scotland although its provision is variable. It should also be noted that the Mental Health (Care and Treatment)(Scotland) Act 2003⁸⁰ identifies the right to independent advocacy for every person with mental disorder and this is not confined to those who are subject to compulsion under the 2003 Act. There is also a corresponding duty on health boards and local authorities to secure the availability of such advocacy⁸¹.

3.1.2. England and Wales

The Mental Capacity Act 2005 (MCA) provides for various forms of support for persons who are deemed to lack capacity. Moreover, section 1(3) expressly 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.’ However there is relatively little guidance about what such steps should involve.

In terms of advance planning, the MCA provides for Lasting Powers of Attorney⁸² in which the donor (P) confers on the donee (or the donees) authority to make decisions about personal welfare and property matters.

Advance decisions are also recognised⁸³. These can be made by a person of 18 years of age or over who has capacity allowing for a treatment specified in the advance decision (even if expressed in layperson’s terms and not in writing) to not be carried out or continued in the event of her or his future incapacity. The person may also withdraw or alter an advance decision at any time when he has capacity to do so⁸⁴. A person does not incur liability for carrying out or continuing treatment unless, at the time, he is satisfied that an advance

⁷⁷ M L Ross. ‘The Adults with Incapacity (Scotland) Act 2000: A Long and Winding Road.’ (2003) 7 *Edinburgh Law Review* 226, 229.

⁷⁸ Advance statements are recognised under the Mental Health (Care and Treatment)(Scotland) Act 2003 (ss 275-276) to the extent that clinical staff and the Mental Health Tribunal for Scotland must have regard to such statements.

⁷⁹ *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 at para 103 per Lord Donaldson MR; *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 WLR 290; *Airedale NHS Trust v Bland* [1993] AC 789.

⁸⁰ S 259(1).

⁸¹ Mental Health (Care and Treatment)(Scotland) Act 2003, s 259(1)(a) and (b). This obligation will be enhanced through Mental Welfare Commission monitoring after provisions in the Mental Health (Scotland) Act 2015 (s 26) come into force.

⁸² MCA, s 9(1).

⁸³ MCA, s 24.

⁸⁴ MCA, s 24.

decision exists which is valid and applicable to the treatment⁸⁵. Further safeguards exist in that a court may declare whether an advance decision exists, is valid, is applicable to a treatment⁸⁶. However, there are limits to the effectiveness of advance decisions in that they cannot prevent a person providing life-sustaining treatment, or doing any act he reasonably believes to be necessary to prevent a serious deterioration in P's condition while a decision as respects any relevant issue is sought from the court⁸⁷.

Finally, the MCA provides for support in the form of 'independent mental capacity advocates' (IMCAs) who are available to represent and support persons in the cases of provision of serious medical treatment by the NHS or accommodation by the NHS or local authorities⁸⁸. The role of IMCAs has however been limited. Under the MCA, the involvement of an IMCA is envisioned primarily at the stage when a best-interests decision is being considered, with their role being in the first instance to involve the person as much as possible in the substitute decision-making process.⁸⁹ Moreover, the MCA Code of Practice states that the IMCA function is designed to support persons "who have no family or friends that it would be appropriate to consult about those decisions."⁹⁰

3.1.3. Northern Ireland

The Mental Capacity Bill (as introduced), currently before the Northern Ireland Assembly, is based in many respects on the English and Welsh Mental Capacity Act 2005 but goes further in terms of support provision. Clause 5(1) of the Bill states that a person is not to be regarded as being unable to make a decision for themselves and thus lacking capacity unless they have been given 'all practicable help and support to enable him or her to make a decision unless, in particular, the steps required by this section have been taken so far as practicable.' Clauses 5(2) and (3) set out those steps are being:

- '(2)...(a) the provision to the person, in a way appropriate to his or her circumstances, of all the information relevant to the decision (or, where it is more likely to help the person to make a decision, of an explanation of that information);
- (b) ensuring that the matter in question is raised with the person—
 - (i) at a time or times likely to help the person to make a decision; and
 - (ii) in an environment likely to help the person to make a decision;
- (c) ensuring that persons whose involvement is likely to help the person to make a decision are involved in helping and supporting the person.

(3) The information referred to in subsection (2)(a) includes information about the reasonably foreseeable consequences of—

- (a) deciding one way or another; or
- (b) failing to make the decision.'

⁸⁵ MCA, s 26.

⁸⁶ MCA, s 26(4).

⁸⁷ MCA, s 26(95).

⁸⁸ MCA, ss 35, and 37-39.

⁸⁹ MCA s 36(2)(a).

⁹⁰ Code of Practice to the MCA, p. 178.

Clause 68 also allows a person who is 16 or over to appoint a ‘nominated person’ such appointment to remain effective even where the appointer no longer has capacity to make decisions about his or her nominated person. A person with capacity can also make a declaration stating that a person/persons named in the declaration is not to be appointed their nominated person⁹¹. There is also provision for the appointment of a default nominated person where a person is over 16 and has not appointed a nominated person such person being chosen from a prescribed list e.g. their carer, spouse, parent, child etc⁹².

Independent advocates must also be instructed by Health and Social Care trusts ‘to represent and provide support to a person (“P”) in the determination of whether a particular act in relation to which P lacks capacity would be in P’s best interests’⁹³. The Department of Health may also make regulations⁹⁴ that, amongst other things, require certain steps to be taken by an independent advocate such as providing support to P so that P may participate as fully as possible in any relevant decision, obtaining and evaluating relevant information, ascertaining P’s past and present wishes and feelings, and the beliefs and values that would be likely to influence P’s decision if P had capacity, ascertaining what alternative courses of action are available in relation to P, informing persons responsible for determining what would be in P’s best interests of the independent advocate’s conclusions and informing P’s nominated person (if any) of matters relevant to the nominated person.

3.2. Examples from other jurisdictions

3.2.1. Canada

3.2.1.1. Representation Agreements – British Columbia

Under the Representation Agreement Act 1996 an individual can enter into a representation agreement with another person who will provide them with decision-making assistance. The Act contains a presumption of capacity. The individual can authorise their representative to help them to make decisions, or to make decisions on their behalf. Decisions can include management of the adult’s financial affairs and major or minor health care. Oversight of the agreement is carried out by a ‘monitor’ who is an individual named in the representation agreement to ensure that the representative is acting honestly, in good faith, and with the care, skill and diligence of a reasonably prudent person.

3.2.1.2. Supported Decision-Making Authorisations – Alberta

Supported decision-making authorisations are personal appointments where an adult forms an agreement with one to three other people, known as supporters, to assist them when making a lifestyle decision. The adults who might utilise these supported decision-making authorisations are described as having the capacity to make their own decisions but ‘would like to have someone they trust help them in the decision-making process.’ A decision made with the assistance of supporter is deemed to be the decision of the supported adult for all

⁹¹ Clause 75.

⁹² Clause 71.

⁹³ Clause 84.

⁹⁴ Clause 85.

purposes. In this regard, the supporter is not liable for anything done or omitted to be done in good faith while exercising the authority or carrying out the duties of the supporter.

3.2.1.3. Personal Directives – Alberta

A personal directive can contain information and instructions about any personal matter. The individual making the directive designates an agent and the directive only has affect when the maker lacks capacity with respect to that matter. The individual making the directive is able to designate a person or persons to determine their capacity. The personal directive ceases to have effect if a determination is made that the maker of the direction has regained capacity to make decisions.

3.2.1.4. Co-Decision-Making – Alberta

A system of co-decision-making operates in the Canadian province of Alberta. Under the Adult Guardianship and Trusteeship Act a co-decision-maker can be appointed for an adult if the court is satisfied that: the adult's capacity to make decisions is significantly impaired; the adult would have the capacity to make decisions about the matters specified in the order if they were provided with the appropriate support and guidance; less intrusive and less restrictive measures have been considered; it is in the adult's best interests. Co-decision-making orders are made by a court and must be made with the consent of the adult.

3.2.2. Sweden

3.2.2.1. Personal Ombudsman

In Sweden a programme of supported decision-making operates for individuals with psychosocial disabilities, called Personligt Ombud or Personal Ombudsman. The ombudsman works exclusively for the individual and is not connected to any other body or organisation. A vital aspect of the programme is the relationship that is built between the ombudsman and the person being supported – only once trust has been established will the individual be able to communicate to their ombudsman what kind of support they want. The Council of Europe paper notes three main reasons for the success of the personal ombudsman model – (i) there is no bureaucratic procedure – an individual can simply state that they wish to have a personal ombudsman; (ii) the ombudsman is flexible and can have contact with the individual at any time; (iii) the ombudsman can support the client with a range of matters, not only those which are the concerns of the authorities.⁹⁵

As there is no formal procedure for appointing a personal ombudsman there is no need for consideration of the capacity of the individual. Studies have shown that when individuals establish contact with a PO, they move away from using expensive psychiatric care and income support and towards rehabilitation, employment, psychotherapy etc. which has economic benefits.

In its 2014 Concluding Observations, the Committee on the Rights of Persons with Disabilities acknowledged that Sweden had abolished declarations of incapacity but noted its concern that the appointment of administrators continues and that this is a form of substitute

⁹⁵ Council of Europe, 'Who gets to decide? – Right to legal capacity for persons with intellectual and psychosocial disabilities' (20 February 2012)

decision-making. It recommended that Sweden take immediate steps to replace substitute decision-making with supported decision-making. No reference was made to the PO system.

3.2.3. Ireland

3.2.3.1. Decision-Making Assistance Agreements

Under the Assisted Decision-Making (Capacity) Act 2015, an individual may appoint a person to assist them in decision-making in relation to their personal welfare and/or property and affairs. The appointer may appoint more than one decision-making assistant. The functions of the decision-making assistant include assisting the appointer to obtain the appointer's relevant information, advising the appointer by explaining relevant information and considerations relating to a relevant decision, ascertaining the will and preferences of the appointer on a matter the subject or to be the subject of a relevant decision and assist the appointer to communicate them; assist the appointer to make and express a relevant decision, and endeavour to ensure that the appointer's relevant decisions are implemented.

The Act also makes provision for co-decision-making wherein a person may appoint a co-decision-maker in relation to one or more decisions concerning the individual's personal welfare and/or property and affairs. Where there is a co-decision-making agreement a decision which is not made jointly by the appointer and co-decision-maker is null and void.

3.2.4. Australia

3.2.4.1. ALRC – Commonwealth Decision-Making Model

The Commonwealth Decision-Making model consists of supporters and representatives. The supporter and representative model would be used in particular areas of Commonwealth law, tailored to suit the legislative context. The ALRC proposes supported decision-making on a spectrum which ranges from an individual appointing a supporter to assist them to make decisions, to fully supported decision-making which involves appointment of a representative by the individual or a court or tribunal. A supporter is an individual or organisation appointed by a person who may require decision-making support to enable them to make a decision. Ultimate decision-maker power remains with the person who requires the support and they may appoint whoever they choose to be their supporter(s). A representative is an individual or organisation appointed by a person who requires decision-making support or by a court or tribunal, to support the person to make decisions and express their will and preferences; determine the person's will and preferences and give effect to them; or consider the person's human rights relevant to the situation in making a decision where their will and preferences cannot be determined at all. A representative would be appointed as a last resort.

In its Concluding Observations published in 2013, the Committee on the Rights of Persons with Disabilities acknowledged the ALRC's work but highlighted its concern that substitute decision-making would be retained. The Committee recommend that Australia use the inquiry to take steps to replace substitute decision-making with supported decision-making.

3.2.4.2. South Australia's Stepped Model

The Australian state of South Australia makes use of a stepped model of supported and substitute decision-making. The stepped model describes different interventions based on the

level of autonomy that is retained by the individual, and the level of intervention by the state. The stepped model identifies different stages/degrees of decision-making ranging from guardianship to autonomous decision-making. In the South Australian trial, agreements were established between a person requesting support and their nominated supporter. Participants were educated to enable them to make a decision about whether to enter into an agreement. The person receiving the support must have been able to express a wish to receive support; form a trusting relationship with another person/s; indicate what decisions they wanted support for; indicate who they wanted to receive such support from; express a wish to end the support if necessary; be aware that they are making the final decision and not their supporter. The trial excluded individuals with psychosocial disabilities. Less than half of those initially interested in the project actually went on to make supported decision-making agreements. This was often because the individual was isolated and did not have a family member or a friend who could act as supporter, or because there was significant conflict among family and friends. A monitor was also appointed as part of the agreement who oversaw the process and acted as a safeguard.

3.2.5. Bulgaria

In Bulgaria the Natural Persons and Support Measure Bill is currently under discussion. The Bill provides that ‘any person, irrespective of the type of their disability, shall be entitled to appropriate support for the purpose of independently exercising his/her rights.’ The Bill provides for a range of support measures which can be provided to an adult as determined by a court. Types of support measures include, referring the person to a community-based social service to help improve their skills and identifying an individual who has a relationship of trust with the adult and who can consent on their behalf in relation to certain legal actions.

3.2.6. Kenya

The Kenyan Mental Health Bill 2014 had its first reading in June 2014. The Bill sets out the rights persons with mental illness and incorporates the right to legal capacity into section 17. While there is a duty on the government to take appropriate measures to provide access to support for persons with mental illness to exercise their legal capacity, the Bill still permits and provides for determinations of incapacity. Under the Bill, if an individual is determined to lack legal capacity, a personal representative is appointed by the court. Significantly, the Bill requires that the will and preference of the individual is the principal consideration when making a decision under the Act, subject to the caveat that due regard is given to the interests of other persons who may be at risk of serious harm.

The Kenya National Commission for Human Rights published a briefing paper on legal capacity in 2014 which provides some examples of supported decision-making taking place across Kenya and makes recommendations to the Law Reform Commission and Kenyan government. In the Committee on the Rights of Persons with Disabilities 2015 Concluding Observations on Kenya, it does not mention the 2014 Bill but recommends that the State party repeal legislation permitting the deprivation of legal capacity and support and facilitate ongoing initiatives to implement article 12, including research by the Kenya National Commission on Human Rights.

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