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Legislating personhood: realising the right to support in exercising legal capacity

Eilionoir Flynn
Centre for Disability Law and Policy, National University of Ireland, Galway

and

Anna Arstein-Kerslake
Centre for Disability Law and Policy, National University of Ireland, Galway

Abstract

This paper examines the regulation of 'personhood' through the granting or denying of legal capacity. It explores the development of the concept of personhood through the lens of moral and political philosophy. It highlights the problem of upholding cognition as a prerequisite for personhood or the granting of legal capacity because it results in the exclusion of people with cognitive disabilities (intellectual, psychosocial, mental disabilities, and others). The United Nations Convention on the Rights of Persons with Disabilities (CRPD) challenges this notion by guaranteeing respect for the right to legal capacity for people with disabilities on an equal basis with others and in all areas of life (Article 12). The paper uses the CRPD to argue for a conception of personhood that is divorced from cognition and a corresponding recognition of legal capacity as a universal attribute that all persons possess. Finally, a support model for the exercise of legal capacity is proposed as a possible alternative to the existing models of substituted decision-making that deny legal capacity and impose outside decision-makers.

Introduction

Granting and denying personhood has been an enigmatic challenge and fascination of human society since the dawn of civilisation. In the past, an individual's legal personhood has been defined by social statuses; for example feudal roles and Roman clan membership (Rehbinder 1971). Women were denied full legal personhood in most jurisdictions up until the last century (Freeman 1989–1990), with Blackstone describing the legal status of women entering marriage as 'civil death', because upon marriage women's legal identities became subsumed within the legal status of their husbands (Blackstone 1979). Under the law of the American colonies, slaves were only thought of as three-fifths of a person.[1] Now, it is largely recognised that social status, skin colour and gender, among other categories, are not legitimate reasons for denying legal personhood to an individual. This is partially based on the notion that those characteristics of an individual do not have an effect on his or her cognitive functioning. In the past, those of a different race or gender to the dominant group were thought to be not only socially, but biologically and cognitively, inferior. Changing social mores, increased access to education, and scientific advances helped to dispel these myths (although science can also rationalise discriminatory distinctions, as evidenced by the eugenics movement). The dominant discourse on legal personhood has prized cognition and

1 The United States Constitution, Article 1, Section 2, Paragraph 3; The House Joint Resolution proposing the 13th amendment to the Constitution, 31 January 1865; Enrolled Acts and Resolutions of Congress, 1789–1999; General Records of the United States Government; Record Group 11; National Archives.

rationality as indicators of autonomy, and distinguishing features between human persons and others not deserving of legal personhood.

Due to the emphasis on cognition and rationality, many people with disabilities (especially individuals with intellectual and psycho-social disabilities) are at a particular disadvantage in terms of recognition of their legal capacity. Considering the reality of scientific limitations, we have very little knowledge at present of the decision-making or communicative functions of the brain. For the most part, we know very little about how people make decisions (Lehrer 2009), and, as a consequence, we should be slow to deny the right to have one's decisions respected by the law to anyone, even where it is difficult to decipher the person's wishes, or where the individual has a different worldview, even one which may seem irrational or ill-informed.

Spurred by the 2007 United Nations Convention on the Rights of Persons with Disabilities (CRPD), there is an emerging consensus in international human rights discourse on the notion that all human persons, regardless of their decision-making capabilities, should enjoy 'legal capacity' on an equal basis – that is, the right to be recognised as a person before the law, and the subsequent right to have one's decisions legally recognised (Minkowitz 2006–2007; Dhanda 2006–2007; Quinn and Arstein-Kerslake 2012). This necessitates the introduction of decision-making mechanisms based on a philosophy of 'support' to replace substituted decision-making mechanisms such as adult guardianship, which treat the individual as more 'object' than 'subject' in relation to exercising rights. The issues of legal capacity, decision-making and recognition as a 'person before the law' are inevitably connected to a broader discourse in philosophy on the nature of 'personhood' and this paper seeks to examine in parallel the notion of legal personhood in the CRPD and its articulation in moral philosophy.

First, we will explore the meaning and application of legal capacity, with particular reference to its value for people with disabilities – and the implications of denying legal capacity to any group of human persons. We will then examine the law's response to challenges which people with disabilities are perceived to have in exercising legal capacity, and these approaches will be analysed from the perspective of both human rights norms and insights from moral philosophy – particularly from Rawls's theory of justice as fairness.

Following this critique, the elements of an alternative approach – a 'support model' of legal capacity – will be outlined, with a view to understanding the practical steps which must be taken to ensure that such an approach can be implemented in any particular jurisdiction. This will be substantiated by examples of how a support model can operate, in practice, to augment an individual's decision-making capabilities, while simultaneously protecting autonomy and self-determination. Our model is distinct from those that have been conceptualised in the past.[2] We will carefully define 'substituted decision-making', setting out the components of this concept which constitute a violation of human rights norms, and then outline a system of support for the exercise of legal capacity that does not include 'substituted decision-making'.[3] Finally, some ethical dilemmas which challenge the new support regime will be outlined, together with suggestions of how both theoretical and practical challenges to supported decision-making can be resolved.

While, in this paper, we address the issue of legal capacity as it affects persons with disabilities, this is an issue for all citizens, and does not require special treatment for people with disabilities. The reason for writing specifically about people with disabilities (and those with intellectual, psycho-social and other cognitive disabilities, in particular) is that these citizens have long been denied the legal capacity that the majority of the population take for granted. However, our

2 Our model builds on the work of Michael Bach and Lana Kerzner in their report in Bach and Kerzner (2010).

3 Furthermore, we favour moving completely away from any test of mental capacity as a means of denoting the person's decision-making status (even a reformed test of mental capacity which allows for capacity being 'shared' between the individual and their co-decision-maker).

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recommendations for support apply to all individuals. This inclusive approach aims to benefit society as a whole, encouraging the active participation of all citizens in the formation and exercise of the social contract.

I Legal capacity and personhood – key concepts from human rights law, guided by moral philosophy

Prior to any analysis of how a support model of legal capacity can be realised, it is important to clearly define the concepts and ideas upon which our argument is based. Throughout this paper, 'legal capacity' is considered to be a possession of the individual. It includes the ability to be a holder of rights (legal status) as well as an actor in law (legal agency) (Office of the United Nations High Commissioner of Human Rights 2005; International Disability Alliance 2008). As a holder of rights with legal status, the state is obligated to protect, promote and enforce the individual's rights. Simultaneously, an individual's legal agency allows her to take actions that the law must recognise; such as signing a contract, getting married, voting and making medical decisions (McSherry 2012). Gerard Quinn asserts that:

> '[L]egal capacity to me is a continuum that connects with everything needed to enable the person to flourish – a right to make decisions and have them respected, a place of one's own, a life in the community connected to friends, acquaintances and social capital, whether in public or private settings. Personhood is broader than just capacity – and these broader connections serve to augment capacity in a virtuous circle.' (Quinn 2011b)

At the outset, it is important to distinguish between decision-making ability (or 'mental capacity') and legal capacity. All individuals have varying levels of decision-making ability; however, we argue that these abilities should not have any impact on an individual's right to legal capacity. Therefore, irrespective of decision-making ability, every person has an inherent right to legal capacity and equal recognition before the law.

Ideas about the social contract, stemming from moral and political philosophy (including Rawls's Theory of Justice) have proved useful for developing an understanding of human beings having moral responsibility (possessing both legal status and legal agency). As part of the social contract, we understand that all citizens implicitly agree to give up some freedoms in order to enjoy the full protection of and benefit from the law (Locke 1988 [1689]). However, an individual's 'legal capacity' is what gives her access to the benefits that the law provides, and is therefore a key component of social contract theories.

Evolving understandings of legal capacity have been at the centre of a number of debates on the content and application of human rights law.[4] Article 12 is the most recent exposition of this debate. Even at the time the CRPD was being drafted (in the early 2000s) a dispute emerged about a possible difference between capacity for rights (or legal status) – which was argued to inhere in all human persons – and capacity to act or to exercise rights (legal agency), which some states argued was not applicable to certain individuals with disabilities.[5] This debate demonstrates

4 See generally Bartlett *et al.* (2007).

5 United Nations Department of Economic and Social Affairs, Ad Hoc Committee on a Comprehensive and Integral International Convention on Promotion of Rights and Dignity of Persons with Disabilities, Working Group on Rights of Persons with Disabilities, *Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on Promotion of Rights and Dignity of Persons with Disabilities on its Fifth Session*, para 18. U.N. Doc. A/AC.265/2005/2 (23 February 2005), online: ‹http://www.un.org/esa/socdev/enable/rights/ahc5reporte.htm› (last accessed 1 November 2011).

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the resistance of society to recognising individuals with disabilities as equal citizens possessing equal rights. It brings to the forefront the notion that disability is the last frontier (or at least one of the last) in the struggle for civil rights – framing the issue of legal capacity as a right which is accorded to most individuals but which continues to be denied to many people with disabilities.[6]

In recent decades, there has been an increasing swell of support for the notion that almost every human person is capable of expressing her will and preferences with the right support. Scientific research is also breaking down the barriers previously thought to exist between logic and intuition in understanding how we make decisions.[7] This work highlights the fallacy of relying on cognition and rationality as benchmarks for recognising personhood and enabling participation in legal systems. In recent scholarship on moral philosophy, a holistic and inclusive notion of personhood has emerged, one not premised on cognition or rationality, but on the 'communicative and semantic aspects of human capabilities' (Jennings 2010), which is the vision adopted throughout this paper as we explore the right to support in order to enable individuals to express their will and preferences, and ultimately, to exercise their legal capacity.

The human rights perspective provided by Article 12 of the CRPD builds on this conception of personhood as it identifies that an individual has a right to legal capacity irrespective of whether or not they have a disability, and simultaneously recognises that some people require assistance to exercise their legal capacity.[8] It therefore requires states to support individuals who require assistance and to safeguard against abuse within that support system.[9] Throughout this paper, this approach is referred to as the support model of legal capacity. One means of providing this support can be for the individual to identify a trusted person or group of people who can support them to express their choices and affirm their decisions. This mechanism is generally referred to as supported decision-making, as contrasted with substituted decision-making – systems such as adult guardianship, which take away an individual's power to make decisions for themselves. Throughout this paper, we define 'substituted decision-making' as systems which rely on an assessment of 'mental capacity' or decision-making ability, to remove the legal right to make a decision from an individual and vest this authority in a third party who will make the relevant decision in the objective or perceived 'best interests' of the person.[10]

In general, the 'substituted judgment' model requires the decision-maker to act in the way that she thinks the person would have wanted, if she were in a position to communicate her wishes. Broadly speaking, this could fit within the 'will and preference' paradigm favoured in Article 12 and articulated in further detail below. However, some substitute judgment models are premised on an assessment of mental capacity and are most often used in cases where cognitive decline is linked to the ageing process, where the individual is presumed to have possessed mental capacity for the decision in question in the past, but is thought to no longer be capable of making the decision. Therefore, the terminology we favour in this paper is that of 'will and preference', which

6 See generally Dhanda (2006–2007) at 433.

7 See, for example, Lehrer (2009), Gigerenzer (2007) and Damasio (2010).

8 United Nations Convention on the Rights of Persons with Disabilities, art. 12, 13 December 2006, 3 U.N.T.S. 2515.

9 The Department of Economic and Social Affairs (UN-DESA), the Office of the United Nations High Commissioner for Human Rights (OHCHR), and the Inter-Parliamentary Union (IPU), *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities, Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and Its Optional Protocol*, The Department of Economic and Social Affairs (UN-DESA), the Office of the United Nations High Commissioner for Human Rights (OHCHR), and the Inter-Parliamentary Union (IPU) (2007), online: ‹http://www.ipu.org/PDF/publications/disabilities-e.pdf›.

10 This definition of substitute decision-making should be carefully distinguished from a 'substitute judgment' model of decision-making. See Jaworska (2009).

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we feel better reflects the approach to decision-making which should occur within the support model of legal capacity.

Article 12 requires a support model of legal capacity to include a permanent presumption in favour of the will and preferences of the individual (Quinn 2011a). It requires that the individual with the disability maintains legal personhood – is not denied her legal capacity. The individual is the decision-maker (Minkowitz 2006–2007), and the role of supporters is confined to explaining details of the decision to be made and interpreting the wishes of the individual where necessary (Bach and Kerzner 2010). In the following section, we explore the historical exclusion of certain groups from recognition of legal capacity, and the current approaches which continue to restrict the rights of people with disabilities, with a view to setting out some opportunities for reform.

II The law's response to challenges in exercising legal capacity

Throughout history, many categories of persons have been regarded as less deserving of equal rights, and indeed as 'less human', than others. This approach to personhood has been used throughout history to justify discriminatory treatment for various individuals and groups, as described in the 'Introduction'. Similarly, people with disabilities have historically been perceived as individuals not worthy of legal capacity and instead as a group which must be paternalistically protected by the law.

These examples from history highlight the moral danger in excluding individual human beings from the framework of legal rights – as such an approach leads to the treatment of these individuals as objects to be pitied and cared for rather than as subjects before the law. This danger leads us to argue for an expansive notion of 'personhood' as an inherent characteristic in every human. This then demands – as reflected in the CRPD – that equal recognition before the law and support in the exercise of legal capacity are basic rights which should be accorded to all.

State responses to the question of who should be deemed to have legal capacity have been to restrict the exercise of legal capacity to those who are deemed as worthy at any given point in time – often based on notions of rationality and cognition. In order to restrict the legal capacity of individuals, the vast majority of jurisdictions around the world currently operate substituted decision-making systems, such as adult guardianship, where an individual's capacity can be assessed and either partially or fully removed in relation to particular decisions or all aspects of life. Guardianship is not the only mechanism for removing or overriding a person's legal capacity; other restrictive laws also exist which enable persons with psycho-social disabilities to be involuntarily detained and forcibly treated,[11] or which exclude people with certain disabilities from consenting to sex,[12] engaging in binding legal contracts,[13] voting[14] or

11 Laws allowing for involuntary detention and forced treatment can currently be found in a majority of jurisdictions around the world. For a discussion of forced treatment and involuntary detention in Europe, see Bartlett *et al.* (2007) at 11–13, 31–74, 130–31. In the light of the CRPD and art. 12, Tina Minkowitz has argued convincingly that forced treatment is a violation of art. 12, the right to legal capacity, as well as rights contained in other human rights instruments: Minkowitz (2006–2007).

12 See, for example, Criminal Law (Sexual Offences) Act 1993 [Ireland], Section 5.

13 In many common law jurisdictions, capacity to contract is not set out in statute and the rules on capacity to enter into enforceable contracts tend to have been developed from equitable doctrines of undue influence and unconscionable bargain. However, two general rules for capacity to contract can be inferred from common law cases: (i) that by reason of the person's mental condition at the time they did not understand what they were doing and the effect it would have on their interests; and (ii) that the other contracting party was aware of this lack of capacity. See, for example, *Boughton v. Knight* (1873) LR 3 PD 64 at 72; *Faber v. Sweet Style Manufacturing Corp.* 40 Misc 2d 212, 216 (1969); *Hassard v. Smith* (1872) Ir. 6 Eq 429.

14 See, for example, *Kiss v. Hungary*, 38832 Eur. Ct. H.R. 06 (Sect. 2) (2010), where the Court found that a blanket restriction of the right to vote for individuals under guardianship based on a finding of mental disability was a

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marriage,[15] or enable people with certain disabilities to be sterilised without their consent, among others.[16] The support model of legal capacity requires all of these systems to be reformed; however, in this paper we will focus primarily on reform of substitute decision-making mechanisms such as guardianship.

Assessments of mental capacity which result in the denial or restriction of legal capacity generally fall under one of three approaches: status, outcome or functional.[17] Under the *status approach*, an individual is denied legal capacity based on the status of the individual as disabled. In this system, there is a presumption of incapacity that is generally predicated on a medical diagnosis of impairment. An example of the status approach can be found in Ireland, where a 'ward of court' is defined as 'a person who has been declared to be of unsound mind and incapable of managing his person or property'.[18]

Under the *outcome approach*, an individual's legal capacity is denied or restricted based on the perception that the individual has made a poor decision. For example, where an individual voluntarily goes into an institution for psychiatric treatment, but becomes unhappy with the treatment and attempts to leave, legal restrictions may be introduced to prevent the individual from leaving. In these cases, the decision to leave (assumed to be a poor decision) is perceived as evidence for grounds to restrict the individual's legal capacity to act on the decision.[19] In this way, the outcome approach is very similar to the status approach in that once the individual is diagnosed as 'disabled' her decision-making skills are automatically questioned (Dhanda 2006–2007).

Under the *functional approach*, an assessment is carried out to determine whether, at the pertinent time, the individual understands the meaning and consequences of the decision at issue. The general components of the test are whether the person can use, weigh and retain information in order to make a decision, understand the consequences of the decision and communicate the decision to others.[20] If it is found that the person does not meet the prescribed standard, then the individual's legal capacity is denied. A typical example of this can be found in the Mental Capacity Act 2005 (England and Wales). The Act states that a person lacks capacity on a matter where 'at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain'. It then defines a person who is unable to make a decision for himself as someone unable 'to understand the information relevant to the decision, to retain that information, to use or weigh that information as part of the

not a legitimate ground for restricting the right to vote. While this ruling was a positive step for the right to vote for people with disabilities, the constitution in Hungary continues to deny people with disabilities the right to vote on an equal basis with others; it states, 'A person disenfranchised by a court for committing an offence or due to his or her limited mental capacity shall have no suffrage', The Fundamental Law of Hungary, art. XXII § 6 (25 April 2011).

15 See, for example, Marriage of Lunatics Act [Ireland] 1811, which makes void any marriage contract entered into by an individual found to be a 'lunatic' by inquisition, which is modernly interpreted as an individual who is placed under wardship. For a further discussion, see The Law Reform Commission [Ireland] (2005).

16 See *Gauer v. France* [Pending] 61521 Eur. Ct. H.R. 08 (2008), where the applicants are five young women with disabilities who allege that they were sterilised without their consent and against their wishes; relevant legislation in France which may be interpreted as allowing for involuntary sterilisation includes: Code Santé Publique [C. San. Pub.] art. 2123-2; Code Pénal [C. Pén.] art. 222-9, 222-10; Code de Procédure Pénal [C. Pr. Pén.] art. 2-8, 575.

17 For a discussion of the legal construction of incompetence and explanations of the various approaches, see Dhanda (2006–2007).

18 Rules of the Superior Courts, Order 67(I)(1) (S.I. No. 15/1986) (Ir.); see also Lunacy Regulation Act 1871 (c. 22/1871) (Ir.).

19 For example, Tex. Health & Safety tit. 7(c), § 572.004 (1991).

20 For example, Mental Capacity Act, 2005 § 3(1) (Eng. and Wales).

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process of making the decision, or to communicate his decision'.[21] Here, while at first glance the focus is on the decision-making skills of the individual, the statute still requires a showing of an impairment, which can quickly circle back to the status based approach. Although the pertinent standard for the removal of legal capacity appears to be the perceived functioning of the individual in relation to decision-making, practically, the person's mental impairment also plays a major role in the determination. Therefore, the functional approach, prima facie seems to not discriminate based on disability, but in practice does just that;[22] although more subtly than the status approach.

The functional approach has become the favoured approach in recent legal capacity law reform.[23] It is perceived to be a more just determination of capacity precisely because it focuses on the behaviour of the individual as opposed to her status as a disabled person. However, even in the functional approach, disability is nearly always a threshold factor, as the assessment is premised on medical evidence of impairment, which is used to disprove that an individual understands the nature and consequence of her actions. Additionally, the functional approach holds individuals with disabilities to a higher standard than that of the general population. For this reason, the application of the functional test is discriminatory on the basis of a medical diagnosis of disability and neither the text of the CRPD nor the UN Committee on the Rights of Persons with Disabilities has commented positively about this approach.

As is evident, the implications of the removal of legal capacity are great – from both a legal and moral perspective. In fact, legal capacity is the backbone of a plethora of other human rights[24] because an individual who is not recognised as a person before the law is automatically deprived of other rights. This demonstrates the inter-connectedness of human rights concerns with deep moral questions about the nature of personhood – a contentious issue that is rarely fully addressed by human rights lawyers, but which cannot be ignored in the context of legal capacity.

As will be explored further below, the language of Article 12 of the CRPD is open to a number of interpretations. Some argue that Article 12 requires the abolition of all forms of substituted decision-making including guardianship, and others argue that some limited forms of guardianship are still acceptable if the appropriate safeguards are in place.[25] However, certain aspects of Article 12 are not open to interpretation. The language of Article 12 clearly suggests that a 'status-based' approach, whereby a person's legal capacity is removed due to the existence of a disability, is no longer permissible in international human rights law.

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21 *Ibid.*, § 2(1).

22 See Frolik (1981), where the author calls functional assessments of capacity a 'legal fiction'.

23 This is the approach set out in the Mental Capacity Act, 2005 § 3(1) (Eng. and Wales) and was advocated as the most appropriate approach for Ireland to follow by the Law Reform Commission (2006). For a discussion of the trajectory of legal capacity law reform, see Booth Glen (2012).

24 For a discussion of the interaction between the right to legal capacity and the right to community living, see Centre for Disability Law and Policy at NUI Galway, 'Submission on Legal Capacity: The Oireachtas Committee on Justice, Defence & Equality', at 23–27, online: ‹www.nuigalway.ie/cdlp/documents/cdlp_submission_on_legal_capacity_the_oireachtas_committee_on_justice_defence_and_equality_.pdf› (last accessed 13 October 2011); for a discussion of why the right to legal capacity is at the heart of the UN CRPD, see Quinn (2010).

25 See Canada's Reservation to the CRPD, art. 12 (11 March 2010). However, the United Nations Committee on the Rights of Persons with Disabilities (CRPD) has recently noted in several of its concluding observations that steps should be taken to replace substituted decision-making with supported decision-making: *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, UN Doc CRPD/C/TUN/CO/1 (11–15 April 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, UN Doc CRPD/C/ESP/CO/1 (19–23 September 2011).

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This has implications for both civil and criminal law. The scope of this paper is limited to the civil context; however, legal capacity plays an important role in several different aspects of criminal law, including criminal culpability, insanity defences, fitness to plead, capacity to consent to sex, etc. Universal legal capacity does not require us to pretend that all people possess the same level of decision-making skills (Dhanda 2006–2007), or require the removal of *mens rea* requirements from the criminal law. To the contrary, it calls for a reassessment of *mens rea* to ensure that it is designed to only allow conviction of those defendants that truly had the intention to commit the crime of which they are accused. It also asks for tests of consent to be conceived equally for those with and without disability. This will require a reassessment of capacity to consent to sex, which sometimes sets out different thresholds for people with cognitive disabilities than for others.[26] While the scope of this paper does not allow a full discussion of this area, it hopes to open up the discussion of further exploration on how to respect the right to legal capacity within criminal law.

Broadly, we argue that Article 12 asserts that legal capacity is inherent in every individual and should never be denied, removed or restricted by the state on the basis of disability or level of decision-making capability.[27] Instead, we argue that Article 12 requires a proactive approach, where states put in place measures to support all citizens in the exercise of their legal capacity, rather than requiring individuals to meet a functional test of mental capacity before their decisions will be legally recognised.

III An alternative legal response – moving towards a support model

The move towards a support model for legal capacity has a basis in human rights law: Article 12 of the CRPD. However, there is a danger in reifying the Convention, and Article 12 in particular, as inevitably this instrument is the product of international compromise, and is deliberately silent on a number of key issues of interpretation.[28] Nonetheless, it does provide us with a positive legal framework within which to operate. Article 12 is a useful starting point for developing domestic legislation based on the support model of legal capacity. For the purpose of clarity, it is worth restating the text of Article 12 in its entirety:

> '1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
> 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
> 3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
> 4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity 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,

26 See, for example, Irish Criminal Law (Sexual Offences) Act 1993 § 5.

27 Legal capacity can be restricted, as always, where an individual breaks the social contract by committing a crime. The focus of this paper, however, is on legal capacity in the civil law context in terms of capacity to exercise rights and uphold responsibilities, rather than 'agency' or 'culpability' in the criminal context.

28 See Amita Dhanda's discussion of the controversial footnote proposed for art. 12, distinguishing between capacity for rights and capacity to act and its removal in the final session of the Ad Hoc Committee, which resulted in a number of reservations to Article 12: Dhanda, *supra* note 6. Also see the Draft General Comment on Article 12, published on the website of the CRPD Committee in October 2013.

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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.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.'

The text of this Article does not specifically require the abolition of substituted decision-making – rather, it switches the focus from deficits or impairments to the supports all individuals use in exercising legal capacity on an equal basis with others.

It could be argued that the language of paragraph four on safeguards (e.g. that measures will apply for the shortest time possible) could be interpreted to apply to either supported decision-making or existing guardianship and substituted decision-making regimes. However, the UN Committee on the Rights of Persons with Disabilities has clearly stated that Article 12 calls for the *replacement* of substituted decision-making systems with supported decision-making systems.[29] We similarly argue that, in fact, reading the Article as a whole,[30] a clear obligation is imposed on states to eliminate substituted decision-making regimes that deny individuals legal capacity and operate on objective 'best interest' standards. This can be seen in the first three paragraphs of Article 12, as well as in the overall object and purpose of the CRPD, which is to firmly establish that people with disabilities have their human rights respected on an equal basis with others. We argue that Article 12, instead, requires States Parties to put in place a continuum of support measures (both empowering and safeguarding individuals' rights) that recognises universal legal capacity and enables all individuals to make decisions which are legally recognised.

Since the entry into force of the Convention, there is an emerging consensus in human rights literature about the direction Article 12 requires us to move in. Scholars have asserted that determinations of incapacity should be eliminated and substituted decision-making systems such as guardianship should be replaced by a system of decision-making that is premised on a support model.[31] While some, including Bach and Kerzner, contend that there may still be room within the support model for an expanded 'functional assessment' of decision-making capability (Bach and Kerzner 2010), which does not entail the removal of legal capacity, but allows individuals to access more intensive forms of support or facilitation in decision-making, we diverge from this view, based on the danger we outline above in such 'functional' assessments becoming status contingent. We do, however, as will be set out below, adopt many of the elements of Bach and Kerzner's model, although we argue that individuals should be able to choose which level of support they require, without undergoing any assessment of their decision-making capability. Therefore, although scholars differ on details of how to operationalise Article 12, there is a general consensus on the move away from status-based systems, and the labelling of individuals as legally incapable, even where this is situation-specific.

29 See, for example, *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations, Tunisia, supra* note 40; *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations, Spain, supra* note 40.

30 Provisions of a treaty must be read in their context and in the light of the object and purpose of the treaty. *Vienna Convention on the Law of Treaties* art. 31(1), 23 May 1969, 1155 U.N.T.S. 331.

31 See generally, *Legal Opinion on Article 12 of the CRPD*, International Disability Alliance, 1 (June 21, 2008), online: ‹http://www.internationaldisabilityalliance.org/representation/legal-capacity-working-group/› Dhanda (2006–2007); Bach and Kerzner (2010); Quinn (2011); Lewis (2011); and Minkowitz (2006–2007).

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Much of the debate on Article 12 and what it means for States Parties to ratify the CRPD initially came from legal academics following the entry into force of the Convention. We will now set out some of the key claims of these scholars in order to contextualise our discussion of the support model of legal capacity. Gerard Quinn has noted that, in many ways, Article 12 embodies the paradigm shift that the CRPD as a whole demands (Quinn 2010). Instead of looking at people with disabilities as a group that suffers from deficiencies, the CRPD requires us to shift our thinking to looking at disability as a function of the individual's interaction with an inhospitable environment; we then have a responsibility to break down those societal barriers to allow people with disabilities the opportunity to flourish. In Article 12, this requires the eradication of barriers to the exercise of legal capacity faced by people with disabilities.

Amita Dhanda argues that Article 12 presents humankind with two fundamental choices:

> 'One recognizes that all persons have legal capacity and the other contends that legal capacity is not a universal human attribute. To ask for the making of the first choice does not mean that it is also being contended that all human beings in fact possess similar capacities. Even as all human beings are being accorded similar value, the differences between them is not being ignored or devalued. The second, on the other hand, recognizes the fact that there are some human beings who do not possess legal capacity and hence can be declared incompetent.' (Dhanda 2006–2007)

Dhanda's own perspective is that the first option is what is required by the CRPD; however, she acknowledges that this could be a big leap for many states to make. She likens this approach to providing equality of opportunity to all while acknowledging the need for difference in treatment between individuals – so, recognising universal legal capacity, but acknowledging that individuals will need different forms of support in order to exercise this. As Bach and Kerzner maintain, this option ensures that the question becomes not whether the person has legal capacity, but what supports are necessary to enable the person to exercise this capacity (Bach and Kerzner 2010). This notion is also premised on the idea that all human persons have the potential to grow and develop, and that states have a responsibility to their citizens to support them to do so, echoing capability theory, as developed by Amartya Sen (Sen 1999).

Legal capacity is a particularly interesting area because of the variety of stakeholders strongly affected by the right. This diversity in stakeholders presents important challenges in addressing all the different needs that each group has in realising the right to legal capacity. This is evidenced in the mental health context, where Tina Minkowitz has written on the issue of forced psychiatric interventions. She asserts that non-consensual psychiatric treatment violates the universal prohibition of torture and should be banned (Minkowitz 2006–2007). While this is a controversial issue, it goes to the heart of the recognition of the right to legal capacity. The recognition of the right cannot merely extend to the areas in which we are all comfortable, because the right to legal capacity is virtually meaningless unless it is fully recognised in all areas of an individual's life. Minkowitz argues convincingly that any denial of the right to legal capacity is a violation of an individual's fundamental human rights and should not be permitted (Minkowitz 2006–2007). This is an important concept for any individual that is at risk of having her legal capacity restricted.

Since the UN Committee on the Rights of Persons with Disabilities began to examine state reports, attention has focused on the Committee and how progressive its interpretation of Article 12 might be – given the very different perspectives on Article 12 put forward by various countries during the treaty negotiations. To date, the Committee has considered the reports of six countries (Tunisia, Spain, Peru, Argentina, China and Hungary) – all of which still operate guardianship or

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substituted decision-making systems for people with disabilities, which remove or restrict the person's right to make decisions. In each of its Concluding Observations on these countries, the Committee expressed concern 'that no measures have been undertaken to replace substitute decision-making by supported decision-making in the exercise of legal capacity'.[32] With respect to all countries, the Committee recommended that the states 'review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences'.[33] This approach demonstrates the Committee's acceptance of the need for a support model of legal capacity to be implemented in States Parties to the Convention; however, as yet, little guidance has been given on what steps would constitute progress towards this support model approach.

As legal and human rights jurisprudence on Article 12 is still evolving, Quinn returns to the core philosophy which underpins this approach – which he identifies as the search for personhood:

> 'I see legal capacity as instrumental to personhood. I want to use this vantage point as a rust solvent to clear away some easy or formulaic understandings of Article 12 and to arrive at a conceptual frame that helps us to truly grasp the profound paradigm shift of Article 12.' (Quinn 2010)

In this way, Quinn argues that Article 12 also calls on all of society to recognise the personhood of people with disabilities, because everyone is capable of expressing will and preferences in some way, even where that expression is not easily understood. For Quinn, this is the basis for the human right to legal capacity in Article 12, which is what allows the individual's will and preferences to be respected (Quinn 2010). In keeping with this approach we now turn to moral philosophy for insights into the nature of moral and legal personhood, and how this might guide the legal framework for implementing a support model of legal capacity.

IV Framing a support model of legal capacity within the social contract: insights from moral philosophy

Since law has a number of limitations in framing the support model of legal capacity envisaged by the Convention, it is necessary to draw deeper on the tradition of moral philosophy to consider the basis for a just legal response to this issue. Many theorists from the moral philosophy tradition have attempted to ascertain what justice requires in terms of a state response to people with disabilities – especially those who might use unconventional forms of communication or expression (e.g. people with intellectual or psycho-social disabilities, who may not communicate through speech). The question of legal capacity is one of the most difficult to resolve – as social justice theorists from Kant onwards have asserted the need for the state to refrain from interference with an individual's autonomy – but in recent decades, the need for a more flexible approach has emerged – one which protects from unwanted interference but simultaneously recognises the interdependence of human decision-making and includes proactive measures to support individuals to exercise their legal capacity to make decisions.

32 *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations of the Committee on the Rights of Persons with Disabilities*, Committee on the Rights of Persons with Disabilities: Fifth session, 4 (11–15 April 2011), online: ‹http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session5.aspx›.

33 *Consideration of Reports Submitted by States Parties under Article 35 of the Convention: Concluding Observations of the Committee on the Rights of Persons with Disabilities*, Committee on the Rights of Persons with Disabilities: Sixth session, 5 (19–23 September 2011), online: ‹http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session6.aspx›.

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Among the many theories of justice based on the social contract, Rawls's remains widely acknowledged as one of the most enduring, and provides one of the most inclusive attempts to rationalise how political and social institutions should operate (Kukathas and Pettit 1990; Nussbaum 2006). For this reason alone, it is worth considering whether people with cognitive disabilities can fit within Rawls's conception of the social contract. However, there are two specific concepts within the Theory of Justice that are particularly relevant to the legal and moral personhood of people with disabilities and the ways in which these individuals exercise their legal capacity. The first is Rawls's conception of the person, which focuses on the political nature of the person, rather than providing a sociological or epistemological description of personhood. Rawls articulates his conception of the person in order to determine how society should operate, and this is arguably more inclusive than descriptive, quasi-scientific descriptions of personhood. This is particularly significant for people with significant and complex disabilities who have historically been excluded from political articulations of their claims to justice.

The second idea of particular interest within Rawls's Theory of Justice is the notion of distributive justice. Many scholars have explored the potential of distributive justice to address the social and economic rights-claims of people with disabilities, with particular reference to the support needs that individuals with more significant and complex disabilities may have, and society's responsibility to address these needs (Silvers et al. 1998; Danermark and Gellerstedt 2004; Stein, 2006). Since this paper is primarily concerned with the expression of moral and legal agency through the prism of legal capacity, we will focus on what the support needs of individuals with disabilities might be in order to enable them to exercise their legal capacity, and consider how these needs might be met within the framework of distributive justice.

A detailed overview of Rawls's Theory of Justice as a whole, or a deep analysis of the many implications of the Rawlsian position on the moral and legal agency of people with intellectual and psycho-social disabilities, is beyond the scope of this paper. Instead, we propose to explore two key questions regarding the legal and moral personhood of people with significant and complex disabilities with reference to the Theory of Justice. First, we will examine if people with disabilities, particularly those with significant intellectual and psycho-social disabilities, fit within Rawls's conception of the participating citizens who, beneath the veil of ignorance, establish the framework of laws and protections which will guarantee their claim to justice. Having established that they can fit within this group, based on Wong's potentiality view of Rawls's theory, we will build upon Wong's explorations of what 'enabling conditions' might be needed to enable them to express and exercise their moral and legal agency.

There has long been a difficulty in determining what Rawls's conception of justice as fairness owes people with disabilities who were thought not to be fully co-operating members of society, and Rawls himself called this one of 'the problems on which justice as fairness may fail' (Rawls 1993, p. 21). However, he also suggested that 'perhaps we simply lack the ingenuity to see how the extension [of justice to people with disabilities] may proceed' (Rawls 1993, p. 21), and we would argue that this extension is now clearer through expanding notions of personhood. Many thinkers including Nussbaum (2006), Kittay (1999) and Stark (2007) have subsequently argued that Rawls's Theory of Justice necessitates treating people with intellectual disabilities (in particular) differently from others, and that other theories of justice, based on enhancing human capabilities, should be preferred, as they provide a more just solution for people with disabilities, and fare equally well at ordering society in a way which does justice to all. However, in this paper we will take the approach that Rawls's theory can be interpreted in a way which does not require differentiating between people with disabilities and those without disabilities, as proposed by Wong (2010). We also argue that Rawls's Theory of Justice can provide guidance in shaping a legal framework for a support model of legal capacity.

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In Rawls's Theory of Justice as fairness, one of the primary characteristics of citizens participating in the social contract is that they have the potential to develop what Rawls calls the two 'moral powers', namely, the capacity for a sense of justice (the ability to regard others as equals and engage with them on fair terms) and the capacity for a conception of the good (the ability to determine one's goals and work towards achieving them) (Rawls 1999). On a very limited reading of the two moral powers, it could be argued that some individuals do not meet a minimum threshold required to exercise these.[34]

However, in the context of expanding notions of personhood, it is arguable that all human beings have the potential to develop these moral powers (what Wong terms the potentiality view). This notion has resonance in Vicktor Frankl's assertion that: 'If we take man as he really is, we make him worse. But if we overestimate him ... we promote him to what he really can be ... If we take a man as he *should* be, we make him capable of becoming what he can be.' (Frankl 1972). Therefore, Wong argues that the potentiality view means that all persons should be supported to develop these two moral powers and that this can be done through securing 'enabling conditions' which allow individuals to express their will and preferences. Building upon this assertion, we contend that where legal capacity has historically been denied, the 'enabling conditions' will ensure that people can make decisions which were previously taken by substitute decision-makers, acting on the paternalistic basis of 'best interests'. This is in keeping with the understanding of people with disabilities as moral subjects, rather than objects to be cared for.

Wong suggests that 'enabling conditions' include opportunities such as: belonging to social groups, interacting with adults who are already exercising the two moral powers, developing relationships with family members, classmates, friends and co-workers, and taking ample time to develop capacities (Wong 2010, p. 133). In keeping with the need to provide enabling conditions is the notion that a person's legal capacity should never be removed, as to do so undermines an individual's position as a moral subject and blocks developmental pathways that lead an individual to assert her will and preferences.

Rawls himself acknowledged that, according to the principle of need, citizens' basic needs (e.g. food, shelter and access to social and cultural opportunities) should be met prior to applying both the liberty and equality principles of justice (Rawls 1993, p. 7). Wong argues that the enabling conditions fit within the principle of need and should therefore be secured prior to the application of principles of justice. We argue that the enabling conditions specified by Wong include what we conceptualise as a continuum of support for decision-making, since this would be 'necessary for citizens to understand and to be able fruitfully to exercise those rights and liberties' (Rawls 1993, p. 7).

To those who would argue that such an approach would require the distribution of significant resources to a minority of individuals in our society, we would disagree. The creation of 'enabling conditions' for decision-making will benefit all citizens, although of course it has particular relevance for people with intellectual and psycho-social disabilities, who have traditionally been denied this form of support, and instead segregated and excluded from society. Another counter-argument to this proposal is that there are still a small number of citizens who are not communicating with others in a manner which can be understood, and can therefore not make their will and preferences known. With advances in medical science[35] it is becoming increasingly clear that any distinction between human beings capable of developing the two moral powers and those not capable of developing these is arbitrary, and history has taught us again and again that

34 This is in fact a core element of Nussbaum's argument; see Nussbaum (2006).

35 See, for example, Lehrer (2009), where advances in neuroscience demonstrate that there is no clear distinction between the emotion and intellect in terms of how we make decisions.

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those originally thought incapable are proved capable, once the opportunity to make their voice heard is provided.

Even in the highly unlikely case that science develops to a point where some citizens can definitively be said not to possess the potential to develop the two moral powers, Wong suggests that there are two possibilities. Either we dismiss the concerns of these citizens as not falling within the concerns of moral subjects, or we endeavour to imagine their will and preferences and speak on their behalf (including by referring to past wishes where relevant) (Wong 2010, p. 133). There are dangers inherent in either approach, but we would strongly agree with Wong that the only just approach is to imagine the will and preferences of the person, as at least this keeps the individual within the realm of moral personhood, as 'a self to whom attention must be paid' (Jennings 2010, p. 171). The question of whether this line of argument would lead to extending justice as fairness to non-human life forms is not one which can be addressed within the scope of this paper. However, at a minimum, we would support Wong's contention that all human beings should be provided with enabling conditions to enhance their potential to exercise the two moral powers – a sense of justice and a conception of the good.

V Enabling conditions and the continuum of support: building a support model for legal capacity

In the context of legal capacity, decision-making and choice, the enabling conditions Wong refers to (interacting with other adults, developing relationships with others, taking time to develop one's capabilities) are particularly relevant. Therefore, we have used this notion of 'enabling conditions' to build upon international human rights discourse which calls for a support model of legal capacity to be introduced in domestic legal systems. We refer to the new approach required as the 'support model', the different levels of support which individuals may require within this model as the 'continuum of support', and envisage 'enabling conditions' as ever-present accommodations which enable people to progress along the continuum of support, and ensure that will and preferences remain the core focus of the support model.

This new model comprises a number of core principles which have been referred to throughout the previous sections but are worth reiterating here for the purpose of clarity. The first principle is that every person enjoys legal capacity regardless of her level of decision-making ability, and should be empowered to exercise her legal capacity through the expression of her will and preference. Second, this requires the abolition of any assessment of decision-making ability which results in the loss of legal capacity. Any assessment which takes place in a support model of legal capacity should be centred on the support that is needed in decision-making to augment an individual's existing strengths, rather than the deficits of the individual. Finally, the support model requires the abolition of substitute decision-making which subjects the will of an individual to the dominance of another's will or notion of what is in her 'best interest'. This does not prevent a representative from making a decision for another person who is not expressing her will and preferences in a way which anyone can interpret – rather, it requires representatives making such decisions to do so in a way which attempts to draw out the imagined will and preferences of the person.

The responsibility of the supporter(s) is always to the person being supported – however, this includes the responsibility to provide all information relevant to the decision in a way the person can understand, which could include the views of supporters and others as to the consequences of this decision. Ultimately the goal of the support relationship is to enable the person to express her will and preferences in relation to the decision, after all the relevant information has been provided. It is not to attempt to influence the person's decision. Where someone has a significant

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decision-making disability and may not be able to communicate her views in a way that others can easily understand, this will be a nuanced and complex process, and should not just provide a legal framework for the supporters to take the decision they feel is best.

The support model of legal capacity we describe is premised on a universal approach to legal capacity – i.e. that legal capacity inheres in each individual, regardless of her level of decision-making ability or 'mental capacity'. Therefore, legal capacity – legal standing and agency – remains with the person, irrespective of what supports are put in place to enable the person to express her will and preferences. To some, this may seem to be a semantic distinction – especially where an individual requires significant levels of support, and where, after such support has been provided, the individual may still not express a will and preference which another person can clearly understand and act upon. However, we contend that this is a critical distinction, as this is the only way in which legal personhood remains with the individual – rather than being vested in a third party. Within this universal conception of legal capacity, different levels of support may be required. However, we take the position that these levels of support do not constitute different legal statuses for the individuals.

Bach and Kerzner outline three main points on the continuum of support to exercise legal capacity (Bach and Kerzner 2010): (i) legally independent decision-making; (ii) supported decision-making; and (iii) facilitated decision-making. While they accept that some movement between legally independent and supported can be made, depending on the decision in question, in general they conceptualise these points as distinct 'statuses', and we diverge from this view, as we believe the different points on the continuum could be held simultaneously, and that movement between all points is possible, depending on the decision, and based on the notion that the individual's decision-making capability can almost always be augmented with the right support or enabling conditions.

The first point on the continuum is Legally Independent Decision-Making, where an individual has the ability to make decisions on her own and is recognised as such. This may require reasonable accommodation to assist the decision-making process. One example of this would be ensuring that information relating to the decision is made available in a format which the person can understand, giving the person plenty of time to come to a decision, and enabling the use of informal support where the person can consult those closest to them in making the decision. This point reflects the ways in which most people make decisions – by consulting others, but being free to accept or reject their advice.

The second point is Supported Decision-Making, in which an individual is provided with assistance in decision-making in any and all areas desired. This assistance can take the form of a circle of support, whereby the person chooses a number of trusted individuals to assist in the decision-making process. These should be people who know the individual well, and can help interpret the person's will and preferences and communicate these intentions to third parties, who are obliged to accept the decision as a valid one. It should be noted that support can only be offered to an individual, and she should be free to accept or reject the support – i.e. supported decision-making should never be imposed on an individual against her will. The state should have a role in providing opportunities for support, enabling support agreements to be formalised and ensuring that decisions made through this mechanism are respected by third parties.

The third point is Facilitated Decision-Making, which applies as a last resort, where there is no circle of support or other person who could reasonably interpret the will and preferences of the individual. In this case, an appointed facilitator takes decisions on behalf of the individual, but does so with the will and preferences of the individual at the centre of the decision-making process and in the manner which best augments the person's autonomy and decision-making capability. The facilitator's role is to imagine what the person's will and preferences might be and to make the decision on this basis. This distinguishes facilitated decision-making from substitute

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decision-making, which favours an objective determination of the person's 'best interests', as opposed to prioritising the will and preference of the individual.

It is important to reiterate that, in our view, none of these three points constitute substituted decision-making, which we define as decisions made *on behalf of* the individual by a representative, and which can be imposed against the will of the individual. We define 'substitute decision-making' as being made based on an assessment of mental capacity, or status as a disabled person, where the representative's determination of the individual's 'best interests' is at the centre of the decision-making process – as opposed to the will and preference of the individual. Instead, we contend that all three of these points constitute supports to exercise legal capacity. In the support model, a support person or network will never make a decision *on behalf of* an individual. Instead, they provide whatever support is needed to augment the individual's decision-making capacity.[36] That support may include communication with outside parties, including representation of the individual's will and preferences. Additionally, the concept of 'best interests' decision-making, where 'best interests' is an objective standard determined by a third party, not by the individual herself, does not play a role in the support model.

In the process of supporting an individual to exercise her legal capacity, supporters may disagree as to what the will and preference of the individual really is. Any disagreement among supporters about whether or not the decision is a good one is not relevant – as long as the person has the appropriate information about the risks involved. To resolve this dispute, a higher decision-making body (such as a court or tribunal) should be engaged, to facilitate discussion and, if necessary, take a decision about what the will and preferences of the individual are, if the supporters cannot ultimately agree.

Another important aspect of a support model is that the individual is free to refuse support. This is very important because it places the individual in the position of power and provides additional protection against the support person abusing her position. We must recognise that in the context of mental health experience and/or dementia, there may need to be a specific clause in a support agreement that provides for exactly the circumstances in which an individual would like support even when she is verbally refusing support in a given moment (sometimes referred to as a Ulysses clause). It must be a carefully crafted and safeguarded clause to avoid any form of forced treatment, or the reverse, a lack of support for a person at a time of crisis when the person actually desired the support.

Finally, the role of the supporter(s) is to articulate the will and preferences of the individual – and to support the person to carry out the decision where possible. However, other actors will often be needed to give full effect to the person's decision – so this responsibility to carry out the decision the person expresses does not only lie with the supporters. Third parties will also have to accept the validity of the decision the individual has made with her supporters in order to honour the person's wishes.

These points on the continuum of support are well developed in work done by Bach and Kerzner (2010). Our approach attempts to develop this further as we conceptualise these points not only as discrete locations or categories, but as inevitably interconnected. People may move between the various points, depending on the enabling conditions provided, or other external environmental factors. However, regardless of the position on the continuum which a person may be at, the enabling conditions must be provided at all times – even if these do not result in a perceptible

36 In addition, in a support model, an individual is also free to appoint one or more representatives to make decisions for her, if that is what the individual desires. However, legislation surrounding these types of representative arrangement must also be constructed in a way that the respects the rights in the CRPD and ensures that the individual can challenge the actions of the representative and can make changes to the arrangement, including revoking the designation of a particular representative.

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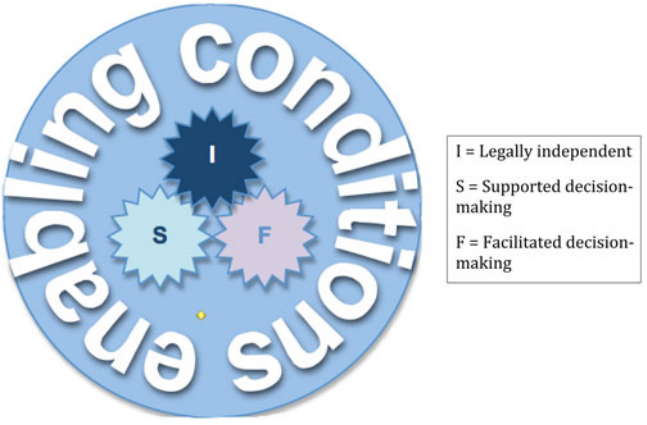

Diagram 1.

increase in decision-making capability for the individual concerned. At the same time, this conceptualisation recognises that a legally independent decision-maker has an equal right to support in certain aspects of decision-making, as an individual who uses facilitated decision-making has to have the tools to enable greater levels of independent decision-making.

Within this continuum of support, it is important to understand that no individual can be 'forced' into one or other of these categories (independent, supported or facilitated) against her will. Facilitated decision-making will never be imposed on a person who is expressing her will and preferences, even where the individual's actions are leading to harm to themselves or others. However, this principle does not eradicate the duty to intervene to assist or safeguard a person, where failure to do so would amount to criminal or civil negligence.[37] This allows every individual the dignity of risk that we are all entitled to. Common challenges to the support model, where individuals are non-responsive or engaging in serious self-harm, are addressed in Section VI.

Certain tools, which could be termed 'enabling conditions' under Wong's interpretation of Rawls (Wong 2010), should be available to facilitate movement throughout the continuum and, in particular, movement from more intensive forms of support (such as facilitated decision-making) to less intensive ones (such as legally independent decision-making). These tools include advocacy support, accessible information, recognition of alternative forms of communication and expression of will and preferences, and the availability of accessible, easily usable, advance planning mechanisms in all fields of decision-making.

Diagram 1 illustrates the relationship, as we see it, between the support model of legal capacity, the three main elements of the continuum of support, and the enabling conditions which allow people to progress along the continuum.

The outer circle represents the overarching support model of legal capacity. The cogs in the centre of the circle represent the three clusters of decision-making: legally independent, supported and facilitated. Surrounding these clusters and captured within the overarching support model are the enabling conditions – which include advocacy, reasonable accommodation, accessible information

37 See, for example, *Donoghue (or McAlister) v. Stevenson*, [1932] 1 A.C. 562 (H.L.), where the court stated: 'You must take reasonable care to avoid acts or omissions which you can reasonably foresee would be likely to injure your neighbour. Who, then, in law, is my neighbour? The answer seems to be – persons who are so closely and directly affected by my act that I ought reasonably to have them in contemplation as being so affected when I am directing my mind to the acts or omissions that are called in question.'

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and communication, recognition of different forms of expression, advance planning tools, and so on. The diagram is intended to demonstrate that the presence of the enabling conditions may move someone from one cluster of decision-making to another – for example, from supported decision-making to legally independent decision-making. Conversely, the absence of the enabling conditions might lead to an individual requiring more intensive forms of support in decision-making, such as a facilitated decision-maker. Even where the enabling conditions are present, external factors, such as the person's environment, might result in the person remaining in the same decision-making cluster for most of their adult life. However, this does not diminish the purpose of the enabling conditions or reduce the obligation to ensure that they are in place.

VI The hard cases: a support model of legal capacity as a universal answer

The questions that always arise in the context of supported decision-making are those of the extreme cases. Where substituted decision-making does not exist, how do you implement a support model when an individual is in a coma and completely non-responsive? Or where an individual is attempting serious self-harm? Realising the right to legal capacity outlined in Article 12 of the CRPD 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 preferences should be left to perish.

Human rights are inherently intertwined. An individual's right to bodily integrity and right to life must be balanced with her right to legal capacity and self-determination. This can be done within the support model of legal capacity in a way that respects all of her rights in parallel. The most important concept to keep at the forefront of this discussion is that, in a support model, the will and preferences of the individual shall always be supreme, regardless of whether outsiders view the resulting decisions as 'good' or 'bad'. Keeping this in mind, as well as an individual's right to bodily integrity and life, we will examine situations in which these rights interact.

One of the most extreme examples used to challenge the support model is where an individual is completely non-responsive – i.e. in a coma or 'vegetative' state. This is clearly a situation in which facilitated decision-making will be required, if the person has not used an advance planning mechanism. Some might argue that to call this 'facilitated' is a fiction – as the representative may never be able to determine what the person would actually have wanted – and that some 'objective' baseline assumptions will need to be used – e.g. a general presumption in favour of life. While we accept this, we maintain that the starting point should always be 'will and preferences', and only where this fails to be conclusive should other considerations be taken into account. While we accept that these extreme cases will always exist, they constitute only a tiny percentage of the decisions which need to be made, and therefore the framework for a support model of legal capacity should not be based entirely on these extreme cases, although such a model does need to be flexible enough to accommodate these situations.

Another extreme example which should be considered is a situation in which an individual is displaying behaviours of serious self-harm. The support model asks those around the person to closely examine what is happening and to support the individual by taking whatever actions are necessary to augment her decision-making ability to a point at which she can clearly express her will and preferences. This could mean a variety of things, including but not limited to assisting the individual in stopping the self-harming behaviour, interacting with the individual in a caring and understanding manner and attempting to create an environment that the individual feels safe and comfortable in to allow her to be in an optimal decision-making scenario. Additionally, a verbal expression in one instance may not necessarily represent the true will and preferences of an individual. For this reason, where an individual is acting in a self-harming manner and may be expressing a verbal preference to continue the behaviour, a support person has a responsibility to

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assist the individual in getting to a place (physically and psychologically) where her decision-making capacity is optimal. We must acknowledge, however, that this does not give a support person free rein to act against the verbal wishes of the person who is being supported. It is only permissible for a support person to act against the explicit instructions of the person being supported when the support person is acting in an emergency situation and where supporting the person's wishes would constitute civil or criminal negligence. We also acknowledge that such emergency situations must be carefully defined so that the exception does not become the norm.

Throughout any interaction, the goal remains of arriving at the will and preferences of the individual. Of course, none of this changes responsibilities that already exist in criminal law and civil negligence law. Therefore, when an individual is engaging in self-harm and is verbally expressing her preference to continue the self-harming behaviour, the support model does not require supporters or others to ignore areas where other law comes into play. The support model can permit this type of interference where it is located within the broader social contract, as discussed above in Section IV. The social contract provides the framework within which we can presume that no individual prefers to be harmed, and where someone is being harmed she would like assistance in ending the harm. There may indeed be situations in which this assumption is not true, where an individual genuinely would prefer to remain in a harmful situation. If the law is being broken, law enforcement will play a role. However, if the law is not being broken and the individual is expressing a choice to remain in a harmful situation, the decision must be respected – as it is for others, such as people who choose to remain in households where domestic abuse is occurring. There is a role for safeguards and monitoring to play here. They must simultaneously ensure that the individual is free to express and act on her true will and preference while also ensuring they are not invading the private life of the individual in an undue manner.

The gravity of these issues highlight the importance of exerting great efforts to discover the true will and preference of an individual and to realise that will and preference to the greatest degree possible. They also demonstrate the need for a thorough understanding of communication mechanisms, both traditional and non-traditional. However, we can acknowledge that in emergency situations, where an individual is engaging in self-harm or is non-responsive, those around the individual have to make quick decisions. In making these decisions, support persons have an obligation to utilise any knowledge they have of the individual's true will and preferences. However, we must also allow and even expect that support people will also use the baseline assumption that any individual would not choose to be in a situation in which they were being harmed. Therefore, a support person is complying with the support model when she removes an individual from a gravely dangerous situation in an effort to assist the individual in getting to a place where the individual can better communicate her will and preferences. This type of intervention, however, should never rise to the level of forced medical or psychiatric treatment.

While the common law duty of care (stemming from the tort of negligence), the defence of necessity, and other laws related to intervention in emergency situations may be used to permit certain interventions, these exceptions and defences need to be extremely limited and carefully defined, to prevent any return to a more regressive system. These types of law must also be re-examined to ensure that they are narrowly tailored to ensure that an individual's rights to health as well as legal capacity are being respected. This means that individuals are free to make decisions for themselves, but also that third parties are protected when they undertake to assist an individual in emergency situations and other circumstances that might trigger a duty of care. The scope of this paper does not allow for a detailed consideration of these exceptions and defences, but rather aims to provide a starting point for further discussion of how these could be thoughtfully framed to reflect the aims of the support model as well as the other Articles in the CRPD.

On the other hand, in a situation in which an individual is merely displaying behaviours that appear unorthodox to an outside observer, but is not causing harm to herself or others, the support model does demand that her decision to engage in the behaviour is respected. At the same time, where an individual is displaying behaviours that not only appear unorthodox but also appear to be signals of a need for outside assistance, the support paradigm asks that a support person work with the individual to ascertain if the individual needs outside support. The problem of interpretation of behaviours is a real one. However, this problem exists in all of our lives and cannot be solved by any legal capacity regime. There will be times in which a person misinterprets another's actions for being a request for support when they are not. In these cases, the support model offers the guarantee that in the end the individual's will and preference will be respected. This means that support persons must focus the majority of their energy on ascertaining the will and preference of the individual, even in the most difficult of circumstances, and must help the individual to attain that preference.

An analogy for this issue can be found in Wong's discussion of choosing a path that is the least morally dangerous.[38] Here, the support model maintains that it is more morally dangerous to impose outside decision-making on an individual than it is to support an individual in her decision-making but ultimately allow her to make her own decisions, be they perceived as 'good' or 'bad' decisions.

In order to explore the practical functioning of a support model, including what types of support should be available in certain circumstances, the following example is drawn from the College of Psychiatry in Ireland (College of Psychiatry of Ireland 2011):

> Example One:
> 'M was an 84-year-old woman with moderate intellectual disability. She did not suffer from a mental illness and was verbal and able to express her wishes clearly. She developed a bony swelling of her left lower leg. She was referred to an orthopedic consultant who recommended a biopsy of her leg, as the most likely diagnosis was a sarcoma. She refused this intervention. She deteriorated rapidly, her leg broke down in weeks, she developed delirium and she died within 2–3 months.' (College of Psychiatry of Ireland 2011).

In this case, a clinician could fear that he would be open to liability for continuing to respect the woman's will and preferences, since this ultimately led to her death. This is an important point, as a support model of legal capacity must provide protection for third parties that enables them to respect the decision of the individual without exposing themselves to civil or criminal liability. In a support model of legal capacity, 'M' would have access to a support person who could help to make sure that the information coming from the medical professionals was accessible for 'M' and that 'M' had the information that she needed in relation to the decision to consent to her leg being biopsied. 'M' would have the ability to refuse that support, if she desired. The medical professionals would have to respect 'M's' decision not to have her leg biopsied, if that was her ultimate decision. The availability of the support person could provide further assurance for the medical professionals that 'M' has been informed of her options and has chosen to refuse life-saving medical treatment, and the medical professionals should not be held liable for respecting 'M's' decision. Because there is no evidence here that 'M's' will and preference cannot be ascertained, a facilitated decision-maker would not be appropriate. This example demonstrates the need to ultimately defer to an individual's will and preferences, where freely and voluntarily given. We must respect an individual's will and preference, even where it goes against the

38 *Ibid.*, at 133.

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recommendation of medical professionals. We cannot presume that a medical professional knows what is best for any individual, as there is much more to an individual than her medical well-being.

The next example provides insight into how support can be provided to an individual in a 'minimally conscious state', and is taken from a case-study within the Irish National Advocacy Service for People with Disabilities.[39]

> Example Two:
> 'Ann, a woman in her fifties with a severe brain injury, described as being in a "minimally conscious state" was referred to an independent advocate by the occupational therapist in the hospital in which she lived. Her medical team had very little knowledge of her as a person, and she had no regular contact with family members. Ann did not communicate in a way in which others could understand. The main issue which was being discussed when the advocate started to work with Ann was where she would be buried after her death.

The advocate attempted a number of communication methods, but was unable to determine Ann's wishes. She then acted as a non-instructed advocate to protect Ann's basic human rights. In the course of this work, the advocate discovered that although 'Ann' was the name on the woman's files, she never responded to this name, and that her real name was Jenny. She found out that Jenny was a mother, a grandmother, a sister, and a widow. Prior to her brain injury, she had worked as a qualified multi-lingual professional, and she loved plants. This new information started to change the care team's view of Jenny, and while previously, the only issue to be discussed was where she would be buried, the advocate was able to initiate new discussions about re-establishing family contact, and recruiting a volunteer to work with Jenny.'

This example of advocacy support demonstrates the importance of recognising the 'personhood' of an individual who has very limited methods of communication, and where no naturally occurring support such as family and friends are present in the person's life. Had a substitute decision-maker been appointed in this case it is likely that the only decisions she would have made, or been involved with, would have related to where Jenny would be buried. This decision-maker would probably have had little or no role in improving Jenny's daily life, or changing the attitudes of her carers towards her. The involvement of an advocate here, however, meant that the focus was firmly on understanding who Jenny was as a person, and using this information to establish what her will and preference might be with regard to her environment, how she spent her day, and with whom.

This case-study is an example of how it is always possible to discover some information about a person, which can be used to 'imagine' her will and preferences, even where the person is in a 'minimally conscious state' and cannot communicate in ways that others understand. It also demonstrates that the decisions which professionals think are important ones to make are not necessarily the most important to the person. With the time and effort of supporters, a bigger picture of the person's life can emerge, which contains more aspirations and expectations for the individual than would exist within a substitute decision-making system.

These examples demonstrate how challenges which seek to undermine the operation of a support model of legal capacity can be resolved within the support paradigm by continuing to refer back to the touchstone of 'will and preferences'. However, this discussion is only in its infancy, and more research is needed to understand how best to ascertain the will and preferences of an individual with significant communicative or cognitive challenges. The suggestions provided here are merely an attempt at a first step in achieving this goal – and we seek only to reaffirm the centrality of

39 This case-study is printed here with the permission of the National Advocacy Service, Ireland.

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'will and preferences' to any legislative framework for implementing a support model of legal capacity.

Conclusion and recommendations for reform

Jones and Basser-Marks (1998) state that the law has a number of serious limitations in bringing about the social, cultural and political change which is required in order to do justice to people with disabilities, and that at best it is only part of any strategy required to provide rights for people with disabilities. While reform of legal capacity law is clearly an important step in achieving a just society, we must remind ourselves that significant cultural and attitudinal change is required at all levels to ensure that people with disabilities' decisions are truly valued as much as others. In reality, we know that many service providers and other third parties have not traditionally given people with disabilities choices, or taken their views seriously. The challenges will be twofold: first, for the support model of legal capacity to filter down to every day life; and second, for supported decision-making that is already happening at the community level to be strengthened and fostered by legal capacity legislation. The more 'enabling conditions' which are made available to people, the less they will be positioned at more intensive forms of support on the continuum of support, e.g. facilitated decision-making.

However, in this paper we can suggest some starting points for the symbolic shift that is needed in our laws on legal capacity. These include abolishing legal determinations of incapacity and front-end tests of decision-making capability that lead to the restriction or denial of legal capacity in some or all aspects of life. Another starting point would be for legal systems to recognise that every individual retains legal capacity regardless of the level of support provided, so that a person with a disability is always viewed as a person before the law. Finally, the recognition of key elements of the continuum of support (legally independent, supported and facilitated decision-making), and the enabling conditions required to exercise legal capacity (advocacy, alternative communication, advance planning, etc.), will ensure that the support model of legal capacity moves from a visionary ideal to a reality in the lives of people with disabilities.

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