

Article 12 of the United Nations Convention on the Rights of Persons with Disabilities and the Legal Capacity of Disabled People: The Way Forward?

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Abstract

Article 12 of the UN Convention on the Rights of Persons with Disabilities provides that disabled people are entitled to legal capacity on an equal basis with others in all areas of life. Crucially Article 12(3) obliges State Parties to provide access to the support that disabled people may require in exercising their legal capacity. Legal capacity is not defined in the Convention. However it can be understood as the construct which gives our decisions and transactions legal significance. Legal capacity is how we give effect to our preferences and choices in the real world. The revolution of Article 12 lays in its demand that disabled people must enjoy legal capacity on an equal basis with others. Thus, disabled people have equal rights to make their own life choices and steer the course of their lives on an equal basis. However, linguistic ambiguity present within Article 12 permits diametrically opposed interpretations of what the provision actually requires. This paper contends that if Article 12 is interpreted progressively, it has the potential to deliver significant improvements in the lives of disabled people. The paper argues for a redefinition of personhood under Article 12 coupled with a move towards supported decision-making models which respect disabled people's equal rights to self-determine. However, this paper also addresses the danger that Article 12's wording may permit the continuation of guardianship-style systems based on substituted decision-making. The continuation of substituted decision-making models could potentially undermine

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the transformative potential of the entire Convention. Similarly, the difficulties of implementing Article 12 effectively might reduce the provision to mere rhetoric. In order to realise the potential of Article 12, State Parties must undertake a process of constructive dialogue through which they can share examples of good practice and assess the outcome of pilot initiatives in order to inform the development of models of supported decision-making. Similarly, States must provide the resources and infrastructure necessary to develop models of supported decision-making. If the disability rights community can encourage State Parties to interpret Article 12 in a manner consistent with the aims of the CRPD then it has the potential to deliver real improvements for the lives of disabled people.

Keywords: Legal capacity, interpretation, equal rights, autonomy, self-determination, guardianship, supported vs. substituted decision-making.

I. INTRODUCTION

This paper examines the potential of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities¹ (hereafter CRPD) to achieve greater substantive equality for disabled people.² It is argued that this can be achieved through improving the opportunities disabled people have to make their own choices and steer the course of their own lives. The paper begins by outlining the provisions of Article 12 and defining the terms which will be used before providing a short outline of the key areas of controversy tackled by the body of the work.

Article 12 of the CRPD requires 'equal recognition before the law'³ for disabled people and Article 12(2) demands that State Parties recognise that disabled people 'enjoy legal capacity on an equal basis with others in all areas of life'.⁴ The lynchpin of

¹ United Nations Convention on the Rights of Persons with Disabilities (opened for signature 13 December 2006, entered into force 3 May 2008) GA Res. 61/106 (January 24 2007) 2515 UNTS 3.

² S Fredman, *Discrimination Law* (2nd edn, OUP 2011) 25–33.

³ UN CRPD (n 1) Art 12.

⁴ *ibid* Art 12(2).

Article 12 is Article 12(3) which obliges State Parties⁵ to provide access to the support disabled people require in exercising their legal capacity.⁶ Additionally, under Article 12(4) State Parties must provide safeguards for all measures which relate to the exercise of legal capacity. Safeguards must be ‘appropriate and effective’ and ensure that all measures relating to the exercise of legal capacity must respect the will and preferences of the disabled person, be free from conflicts of interest and undue influence, be proportionate and tailored to the individual, apply for the shortest time possible and be subject to review by a competent authority or judicial body.⁷ Additionally, Art.12(5) provides that disabled people have equal rights to own and inherit property, control their finances, access financial credit and not be arbitrarily deprived of their property.⁸

Legal capacity is not defined in the CRPD. However, its meaning has been eloquently explained by Oliver Lewis who notes that legal capacity is the construct through which the law can ‘recognise and validate the decisions and transactions that a person makes.’⁹ This definition will be adopted here. Legal capacity is the mechanism which ensures that an individual’s decisions have legal personality. It is how we give effect to our choices and preferences in the real life context. When a person’s legal capacity is respected they are able to enter contracts, consent to medical treatment, marry, and in countless other ways control the course of their own life. Legal capacity consists both of the recognition of a person as a *holder* of rights and the *ability to exercise* those rights.

The CRPD refers to ‘persons with disabilities’¹⁰ and this construction is commendable for placing the person before the disability.¹¹ Nevertheless, the term ‘disabled people’ is preferred by many proponents of the social model of disability¹² and will be

⁵ State Parties are countries or regional organisations (such as the EU) which have ratified the UN CRPD.

⁶ UN CRPD (n 1) Art 12(3).

⁷ *ibid* Art 12(4).

⁸ *ibid* Art 12(5).

⁹ O Lewis, ‘Advancing Legal Capacity Jurisprudence’ (2011) 6 EHRLR 700, 700.

¹⁰ UN CRPD (n 1).

¹¹ A Lawson, ‘The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?’ (2007) 34 Syracuse Journal of International Law and Commerce 563, 572.

¹² *ibid*.

adopted here. Traditionally, disability was conceptualised as a medical deficiency of the individual¹³ prohibiting their participation in ordinary society. Strategies for overcoming the impairment sought to 'cure' the individual 'to become as "normal" as possible'.¹⁴ If the individual could not be 'cured' they remained on the outskirts of society, dependant on charity and social-welfare.¹⁵ Consequently, the disability movement developed a 'social model'¹⁶ of disability, shifting the focus away from individual impairment 'on to the problems caused by disabling environments, barriers and cultures'.¹⁷ The social model distinguishes between impairment and disability¹⁸ establishing that it is the *barriers in society* which 'disable' people with impairments from full participation. Societal barriers should be removed in order to facilitate the inclusion of people with impairments. The CRPD itself embodies a conceptual shift¹⁹ towards the social model: 'recognizing that disability is an evolving concept... result[ing] from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation'.²⁰ In light of this, the reference to 'persons with disabilities' seems to confuse the concepts of disability and impairment;²¹ therefore the term 'disabled people' will be used in this paper. Issues of legal capacity generally arise

¹³ C Barnes and G Mercer, *Exploring Disability* (Polity Press 2010) 18–24.

¹⁴ R Traustadottir, 'Disability Studies, The Social Model and Legal Developments' in O M Arnardóttir and G Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff Publishers 2009) 5.

¹⁵ Lawson (n 11) 572.

¹⁶ C Barnes and G Mercer, 'Understanding Impairment and Disability: towards an international perspective' in C Barnes and G Mercer (eds), *The Social Model of Disability: Europe and the Majority World* (The Disability Press 2005) 1.

¹⁷ Mike Oliver, 'The Social Model in Action: if I had a hammer' in Colin Barnes and Geof Mercer (eds), *Implementing the Social Model of Disability: Theory and Research* (The Disability Press 2004) 20.

¹⁸ Traustadottir (n 14) 10.

¹⁹ Federal Public Service Social Security, 'The UN Convention on the Rights of Persons with disabilities: an Integral and Integrated Approach to the Implementation of Disability Rights' (*Federal Public Service Social Security*, 18-19 November 2010) 12–13 <http://www.socialsecurity.fgov.be/eu/docs/agenda/18-19_11_10_background_document.pdf> accessed 10 September 2013.

²⁰ UN CRPD (n 1) preamble para (e).

²¹ R Kayess and P French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 HRLR 1, 21.

in relation to people with intellectual, psychosocial and cognitive impairments. Consequently, reference to 'disabled people' in this paper primarily refers to them.²²

In referring to 'improvement in the lives of disabled people' the paper means progress towards disabled people gaining equal rights to self-determine. For the purpose of this paper, the right to self-determine can be understood as the rights disabled people have to make their own decisions or life choices. Crucially, this includes the right to have their decisions respected. It is through making decisions such as how we live and how we are educated, that each individual human is able to construct their personhood and establish their own individual notion of a good life. The CRPD purports to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities'.²³ Consequently, this paper examines whether Article 12 can give disabled people the ability and resources necessary to exercise their freedom and 'have the capacity to pursue their valued options'²⁴ on an equal basis with others.

This paper explores what makes Article 12 'one of the cardinal rights and principles of the Convention'²⁵ and why disability activists²⁶ assert that enjoyment of legal capacity under Article 12 is a 'prerequisite for the equal enjoyment of all the other rights

²² People with mental, intellectual and sensory impairments are expressly provided for in Article 1 of the CRPD.

²³ UN CRPD (n 1) Art 1.

²⁴ S Fredman, *Human Rights Transformed: positive rights and positive duties* (OUP 2008) 4.

²⁵ Committee on the Rights of Persons with Disabilities, 'Outline: Day of General Discussion on "Article 12 of the CRPD – The right to equal recognition before the law"' (*United Nations Office of the High Commissioner for Human Rights*, 19-23 October 2009) 1 <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 10 September 2013.

²⁶ See the opinions of the Mental Disability Advocacy Center and the Hungarian Association for Persons with Intellectual Disability, in G Gombos, B Benkó and M Kovács, 'Written submission on the right to equal recognition before the law: Based on the case of Hungary' Submitted to the Committee on the Rights of Persons with Disabilities by the Mental Disability Advocacy Center and the Hungarian Association for Persons with Intellectual Disability (*United Nations Office of the High Commissioner for Human Rights*, 4 September 2009) [14] <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 10 September 2013.

enshrined in the CRPD'.²⁷ This paper orientates the reader within the central controversies surrounding Article 12. It critically evaluates how the unspecific nature of the provision can, and is, being interpreted in diametrically opposed ways by different State Parties and members of the disability rights community in accordance with their differing priorities. This paper demonstrates how Article 12 can be interpreted as a powerful driver for improvement in the lives of disabled people,²⁸ and how it embodies the paradigmatic shift of the CRPD towards respecting the inherent worth, dignity and autonomy of disabled people. Contrastingly, the paper also examines the possibility that Article 12 can be interpreted in a way which legitimises substituted decision-making and may prevent disabled people from exercising control over the decisions affecting their lives.

This paper addresses the challenge for the disability rights community in ensuring that Article 12 is interpreted in a way which overcomes the limitations of its genesis. As Dhanda²⁹ and Quinn³⁰ recognise, in order to achieve universal acceptance, human rights treaties often settle for 'constructive ambiguity'³¹ in their wording. To fully realise Article 12's transformative potential, State Parties must be encouraged to look beyond the ambiguous wording which was needed in order to ensure the CRPD's universal acceptance. Article 12 requires interpretation in line with the general principles of the CRPD which demand respect for the inherent dignity and individual autonomy of disabled people 'including the freedom to make one's own choices',³² as well as 'full and effective participation in society'³³ without discrimination.³⁴ Article 12 is a fundamental expression of the claim by the disability rights com-

²⁷ *ibid.*

²⁸ Gerard Quinn, 'Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD' (HPOD Conference, Harvard Law School, 20 February 2010) 3.

²⁹ A Dhanda, 'Legal Capacity in the Disability Right Convention: Stranglehold of the past or lodestar for the future?' (2007) 34 *Syracuse Journal of International Law and Commerce* 429, 431.

³⁰ Quinn, 'Personhood and Legal Capacity...' (n 28) 4.

³¹ *ibid.*

³² UN CRPD (n 1) Art 3(a).

³³ *ibid* Art 3(c).

³⁴ *ibid* Art 3(b).

munity that there should be ‘nothing about us without us’.³⁵ This article considers whether Article 12’s ambiguity and the difficulty of implementing strategies to support disabled people in exercising their legal capacity, could potentially undermine the transformative potential of Article 12 and by extension the potential of the entire Convention to achieve positive change.

II. THE IMPORTANCE OF ARTICLE 12

Article 12 is arguably the most controversial provision in the Convention. It is also arguably the most important and ‘revolutionary’.³⁶ The revolution of Article 12 lays in its recognition that all disabled people possess legal capacity and have the right to exercise it on an equal basis. Indeed, the UN Committee for the CRPD³⁷ felt the provision was important enough to be the topic of the first ever Day of General Discussion on 21st October 2009.³⁸ However, the controversial nature of Article 12 can be seen in the reality that almost four years after the Day of General Discussion the Committee have yet to produce a General Comment elaborating on the requirements of Article 12. Nevertheless, the Committee are giving hopeful indications that the obligation for State Parties to provide the support disabled people require in order to exercise

³⁵ World Network of Users and Survivors of Psychiatry (WNUSP), ‘Implementation Manual for the United Nations Convention on the Rights of Persons with Disabilities’ (WNUSP, February 2008) 48 <http://www.wnusp.net/documents/WNUSP_CRPD_Manual.pdf> accessed 10 September 2013.

³⁶ T Minkowitz, ‘The United Nations Convention on the Rights of Persons with Disabilities and the Right to be free from non-consensual psychiatric interventions’ (2007) 34 *Syracuse Journal of International Law and Commerce* 405, 408.

³⁷ Office of the High Commissioner for Human Rights, ‘Committee on the Rights of Persons with Disabilities’ (*United Nations Office of the High Commissioner for Human Rights*, 2013) <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>> accessed 10 September 2013.

³⁸ Fiona Given, Joanna Shulman, Rosemary Kayess and Elizabeth O’Brian (New South Wales Disability Discrimination Legal Centre Inc), Committee on the Rights of Persons with Disabilities, ‘Day of General Discussion on Article 12 of the CRPD: The Right to Equal Recognition before the Law’ (*United Nations Office of the High Commissioner for Human Rights*, September 2009), <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 10 September 2013.

their legal capacity,³⁹ will move beyond mere rhetoric and will require States to take positive steps towards implementing supported decision-making. The Committee's Concluding Comments on the reports of Tunisia⁴⁰ and Spain⁴¹ both express concern that neither country has taken measures 'to replace substituted decision-making by supported decision-making in the exercise of legal capacity'.⁴² The Committee has issued Concluding Observations on the reports of seven State Parties to date and all the reports note the importance of Article 12 and recommend that states review laws pertaining to guardianship and implement laws and policies which facilitate supported decision-making.⁴³

Historically disabled people have been systematically denied the ability to make their own decisions or have control over their lives.⁴⁴ Quinn feels disabled people have been treated as 'objects' to be dealt with, rather than 'subjects' with their own interests and rights to exercise.⁴⁵ The reference to 'objects' itself reflects the

³⁹ UN CRPD (n 1) Article 12(3).

⁴⁰ Committee on the Rights of Persons with Disabilities, 'Concluding Observations of the Committee on the Rights of Persons with Disabilities on the initial report of Tunisia' (15 April 2011) UN Doc CRPD/C/TUN/CO/1.

⁴¹ Committee on the Rights of Persons with Disabilities, 'Concluding Observations of the Committee on the Rights of Persons with Disabilities on the initial report of Spain' (23 September 2011) UN Doc CRPD/C/ESP/CO/1.

⁴² Committee on the Rights of Persons with Disabilities, 'Concluding observations of the Committee on the Rights of Persons with Disabilities on the initial report of Tunisia' (15 April 2011) UN Doc CRPD/C/TUN/CO/1, [22]–[23]; Committee on the Rights of Persons with Disabilities, 'Concluding observations of the Committee on the Rights of Persons with Disabilities on the initial report of Spain' (23 September 2011) UN Doc CRPD/C/ESP/CO/1, [33]–[34].

⁴³ The CRPD Committee has published Concluding Observations on the Reports of Tunisia, Spain, Peru, Argentina, China, Hungary and Paraguay. At the time of writing the Committee is meeting at its 10th Session and is due to adopt three further Concluding Observations on the reports of Australia, Austria and El Salvador. All are freely available at Committee on the Rights of Persons with Disabilities, 'Committee on the Rights of Persons with Disabilities - Sessions' (*United Nations Office of the High Commissioner for Human Rights*, 2013) <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Sessions.aspx>> accessed 9 September 2013.

⁴⁴ Michael Bach, 'Supported Decision Making Under Article 12 UN Convention on the Right of Persons with Disabilities: Questions and Challenges' (Conference on Legal Capacity and Supported Decision Making, Athlone, 3 November 2007) <<http://www.inclusionireland.ie/content/page/capacity>> accessed 9 September 2013.

⁴⁵ Gerard Quinn, 'A Short Guide to the United Nations Convention on the Rights

reality that impairment was seen as ‘eroding’⁴⁶ the status of being human. This oppression is ‘exemplified in highly restrictive laws on legal capacity’.⁴⁷

Without legal capacity a person cannot enter contracts, marry or vote. In many countries legal capacity could (and still can) be entirely removed simply on the basis of a medical diagnosis of intellectual or even a physical impairment.⁴⁸ The ability of the disabled person to self-determine is removed solely on the basis of their status of having an impairment.⁴⁹ This approach to removing legal capacity has aptly been labelled the ‘status approach’. Under the status approach disabled people suffer a complete ‘civil death’⁵⁰ regardless of their decision-making capabilities. Similarly, disabled people have often had their legal capacity removed under the ‘outcome approach’ which assumes that if a disabled person makes a decision which appears to be questionable or misguided, then it is assumed that they must be incapable of making their own choices.⁵¹ On losing legal capacity, disabled people often become subject to guardianship systems, which operate on the basis of ‘substituted’ rather than ‘supported decision-making’.⁵² ‘Supported’ decision-making involves the provision of assistance to disabled people which empowers and enables them to make their own choices. However, ‘substituted’ decision-making occurs when a disabled person’s right to make their own decisions is removed and the control of their decisions passes to another person who substitutes their judgement for that of the disabled individual. Substituted decision-making has often occurred through highly restrictive guardianship provisions.

At its worst, plenary guardianship permits the guardian (often

of Persons with Disabilities’ in Gerard Quinn and Lisa Waddington (eds), *European Yearbook of Disability Law: Volume 1* (Intersentia, Hart Publishing 2009) 105.

⁴⁶ *ibid* 89.

⁴⁷ *ibid* 105.

⁴⁸ Dhanda (n 29) 431.

⁴⁹ Mary Keys, ‘Legal Capacity Law Reform in Europe: An Urgent Challenge’ in Gerard Quinn and Lisa Waddington (eds), *European Yearbook of Disability Law: Volume 1* (Intersentia, Hart Publishing 2009) 71; Also see Dhanda (n 29) 431.

⁵⁰ *ibid* 60.

⁵¹ *ibid* 72.

⁵² Lawson (n 11) 569.

a stranger) to make every decision pertaining to a disabled person's life without even an obligation to consider their wishes.⁵³ Guardianship has a long history of abuse. The Mental Disability Advocacy Centre (MDAC) conducted research across various countries⁵⁴ finding 'significant, arbitrary and automatic deprivations'⁵⁵ of the human rights of disabled people who are deprived of their rights to 'property, to a family life... to vote... [and] to access courts'.⁵⁶ Often guardians can place disabled people in social care institutions, against their will, for the rest of their lives. Disabled people often have no right to appeal these decisions.⁵⁷ In *Shtukaturov v Russia*⁵⁸ the applicant was institutionalised (against his will) simply on the basis of his lacking legal capacity. His legal capacity had been removed at the request of his mother 10 months previously. The court hearing which removed the applicant's legal capacity had lasted just 10 minutes without the applicant having knowledge of the hearing or the opportunity to present evidence. The applicant was subject to "full incapacitation" for an indefinite period and was fully dependant on his guardian (his mother), in almost all areas of life. Because the applicant lacked legal capacity under Russian law, he also lacked legal standing to bring court proceedings. The only way the applicant could challenge the removal of his legal capacity was through his guardian, who opposed this action. The European Court of Human Rights (ECtHR) held that the applicant's participation in the court process was 'reduced to zero'.⁵⁹ The Court found violations of the applicant's rights

⁵³ Mental Disability Advocacy Center, 'Guardianship and Human Rights in Russia: Analysis of Guardianship Law and Policy' (MDAC 2007) 7 <http://www.mdac.info/sites/mdac.info/files/English_Guardianship_and_Human_Rights_in_Russia.pdf> accessed 10 September 2013.

⁵⁴ The MDAC has produced comprehensive reports on guardianship in the countries of: Serbia, Russia, Kyrgyzstan, Georgia, Hungary, Czech Republic and Bulgaria, all are available from their website: <<http://mdac.info/resources?goal=All&format=All>> accessed 10 September 2013.

⁵⁵ Mental Disability Advocacy Center, 'Guardianship and Human Rights in Serbia: Analysis of Guardianship Law and Policy' (MDAC 2006) 6 <http://mdac.info/sites/mdac.info/files/English_Guardianship_and_Human_Rights_in_Serbia.pdf> accessed 10 September 2013.

⁵⁶ *ibid.*

⁵⁷ MDAC, 'Guardianship... in Russia' (n 53) 6.

⁵⁸ *Shtukaturov v Russia* App no 44009/05 (ECHR 27 March 2008).

⁵⁹ *ibid* [91].

under Articles 5(1), 5(4), 6 and 8 of the European Convention of Human Rights. The ECtHR held that the existence of even a serious mental disorder ‘cannot be the sole reason to justify full incapacitation’.⁶⁰ While Mr Shtukaturrov was in the psychiatric hospital he was denied access to the telephone, prohibited from seeing visitors or his lawyer, had writing materials withheld from him and his diary confiscated. He also claimed that he was treated with strong medications against his will.⁶¹

Institutionalisation compounds the social exclusion of people with intellectual impairments⁶² and causes learned dependency.⁶³ Instead of supporting the disabled person to develop decision-making capabilities,⁶⁴ guardianship robs them of the opportunity to make their own decisions and develop an individualised notion of the self. Additionally, institutionalisation places disabled people at greater risk of fundamental human rights abuses. MDAC research found extensive violations of dignity and privacy along with inhumane and degrading treatment.⁶⁵ Institutionalisation implies that disabled people need hiding away. This perpetuates prejudice against people with intellectual impairments through lack of visibility. It prohibits social integration and substantive equality which are direct aims of the CRPD.

Without legal capacity under Article 12, the other rights guaranteed in the Convention become meaningless.⁶⁶ Without legal

⁶⁰ *ibid* [94].

⁶¹ *ibid* [25].

⁶² MDAC, ‘Guardianship... in Serbia’ (n 55) 6.

⁶³ Dhanda (n 29) 436.

⁶⁴ Keys (49) 61–62.

⁶⁵ See for example, Mental Disability Advocacy Center and the Association for the Social Affirmation of People with Mental Disabilities, ‘Out of Sight: Human Rights in Psychiatric Hospitals and Social Care Institutions in Croatia’ (MDAC 2011) <http://mdac.info/sites/mdac.info/files/croatiareport2011_en.pdf> accessed 13 September 2013; Also see Mental Disability Advocacy Center, ‘Cage Beds: Inhumane and Degrading Treatment or Punishment in Four EU Accession Countries’ (MDAC 2003) <http://mdac.info/sites/mdac.info/files/English_Cage_Beds.pdf> accessed 13 September 2013.

⁶⁶ Examination of the interconnected nature of every article in the CRPD is precluded here for reasons of space. For a discussion of all the rights affected by the denial of legal capacity see Michael Bach ‘Presentation on Supported Decision Making – What does article 12 of the CRPD require? Theoretical starting points and questions/implications for law and policy’ (July 2009) Inclusion Ireland <<http://www.inclusionireland.ie/content/page/capacity>>

capacity one cannot make fundamental life choices such as deciding where to live,⁶⁷ whether to marry,⁶⁸ how to regulate one's finances⁶⁹ or where to work.⁷⁰ Individuals cannot make healthcare decisions⁷¹ and may be subject to treatment against their will.⁷² A 2012 Fundamental Rights Agency (FRA) report contains self-report data outlining this situation:

'nobody asked me, they talked to my mother and she gave consent. . . nobody had explained to me what exactly electro-convulsive therapy is like'.⁷³

Disabled people may be denied access to justice,⁷⁴ and may be prohibited from enjoying equal rights to education⁷⁵ and participation in political⁷⁶ and cultural⁷⁷ life. It is by making these decisions that each individual exercises the very notion of their humanity and constructs their personhood by establishing their own individualised notion of a good life.⁷⁸ Without the legal capacity presumed necessary to make these decisions, the guarantees in the CRPD will prove meaningless for people with intellectual impairments.

accessed 9 September 2013.

- ⁶⁷ This removes the ability of the disabled person to exercise the rights guaranteed under the UN CRPD (n 1): Art 9 (Accessibility), Art 14 (Liberty and security of the person), Art 18 (Liberty of movement and nationality), Art 19 (Living independently and being included in the community) and Art 22 (Respect for privacy).
- ⁶⁸ UN CRPD (n 1) Art 23 (Respect for home and the family).
- ⁶⁹ *ibid* Art 12(5) and Art 28 (Adequate standard of living and social protection).
- ⁷⁰ *ibid* Art 27 (Work and employment).
- ⁷¹ *ibid* Art 25 (Health).
- ⁷² *ibid* Art 14 (Liberty and security of the person), Art 15 (Freedom from torture, or inhumane or degrading treatment), Art 26 (Habilitation and rehabilitation). For an analysis of the problematic nature of forced medical treatment see Minkowitz (n 36) 409.
- ⁷³ The European Union Agency for Fundamental Rights, 'Involuntary placement and involuntary treatment of persons with mental health problems', (Publications Office for the European Union 2012) 46 [3.2.1] <http://fra.europa.eu/fraWebsite/attachments/FRA-2012-involuntary-placement-treatment_EN.pdf> accessed 10 September 2013.
- ⁷⁴ UN CRPD (n 1) Art 13 (Access to justice).
- ⁷⁵ *ibid* Art 24 (Education).
- ⁷⁶ *ibid* Art 29 (Participation in political and public life).
- ⁷⁷ *ibid* Art 30 (Participation in cultural life, recreation, leisure and sport).
- ⁷⁸ G Quinn, 'An Ideas Paper' (Consortium on Human Rights and Disability, Seminar on Legal Capacity, Brussels 4 June 2009) 9–10. <<http://www.inclusionireland.ie/content/page/capacity>> accessed 10 September 2013.

Article 12 recognises that disabled people are *people*, with equal rights to enjoy their legal capacity.⁷⁹ It moves away from models of substituted decision-making under guardianship, towards supported decision-making. Supported decision-making is ‘the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters’.⁸⁰ State Parties must ‘take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’.⁸¹

Article 12 requires the abolition of any legislation which adopts a ‘status’ or ‘outcome’-based approach to removing legal capacity by equating a diagnosis of intellectual impairment with incapacity.⁸² Unlike the ‘status’ and ‘outcome’ approaches critiqued above, Article 12 adopts a ‘functionalist approach’ which recognises that decision-making capabilities can fluctuate at different times and in relation to different decisions.⁸³ Art. 12 begins with the assumption that all disabled people have capacity.⁸⁴ It adopts an ‘equality-based model that compliments full legal rights to... self-determination with entitlement to support when needed’.⁸⁵ By acknowledging that States must provide access to support as an integral aspect of fulfilling the right to legal capacity, Article 12(3) bridges the distinction between civil and political and socio-economic rights.⁸⁶ Article 12(4) requires that any measures relating to the exercise of legal capacity must ‘provide for appropriate and effective safeguards to prevent abuse’⁸⁷ and ‘must respect the rights, will and preferences of the person’,⁸⁸ be free from conflicts of interest, be

⁷⁹ UN CRPD (n 1) Art 12(3).

⁸⁰ Office of the High Commissioner for Human Rights ‘Thematic Study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities’ (26 January 2009).

⁸¹ UN CRPD (n 1) Art 12(3).

⁸² Minkowitz (n 36) 408.

⁸³ Keys (n 49) 72.

⁸⁴ P Weller, ‘Supported Decision-Making and the Achievement of Non-Discrimination: The Promise and Paradox of the Disabilities Convention’ (2008) 26 *Law in Context* 85, 103.

⁸⁵ Minkowitz (n 36) 409.

⁸⁶ Fredman, *Human Rights Transformed* (n 24) 66–70.

⁸⁷ UN CRPD (n 1) Art 12(4).

⁸⁸ *ibid.*

proportional and tailored to the disabled person's needs, be applied for the shortest time possible and be subject to regular independent review.⁸⁹ Despite the promise of this wording, much controversy surrounds what Articles 12(3) and (4) actually require or permit.

III. CONTROVERSY DURING DRAFTING AND ON-GOING DEBATE

Arguably the most progressive and significant aspect of the CRPD is the process by which it was drafted.⁹⁰ During drafting the Ad Hoc Committee permitted 'all genuinely interested civil society groups'⁹¹ to participate. Crucially, groups did not require consultative status with the UN to contribute. This 'expanded the range of disability groups that could attend. . . [having] a huge impact on the drafting positions of States'.⁹² The groups were arranged into the International Disability Caucus (IDC). The IDC rejected any notion of guardianship provisions in the Convention since a legitimization of substituted decision-making would undermine the general principles of the CRPD by directly contravening the notions of autonomy, non-discrimination and equal participation.⁹³ However, during the Working Group, concerns were raised regarding the small number of disabled people whose intellectual or communicative difficulties were so profound that they 'would not be able to function, even with support and would require others to make decisions on their behalf'.⁹⁴ For some State Parties, this reality should be acknowledged by the Convention and provision made for substituted decision-making subject to safeguards.⁹⁵ The IDC continued to assert that in

⁸⁹ *ibid.*

⁹⁰ A Kanter, 'The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities' (2007) 34 *Syracuse Journal of International Law and Commerce* 287, 308.

⁹¹ Quinn, 'A Short Guide. . .' (n 45) 98.

⁹² *ibid.*

⁹³ International Disability Caucus, 'Article 9: Equal Recognition Before the Law – IDC Response to Article 9' (*UN Enable*, 2003-4) <<http://www.un.org/esa/socdev/enable/rights/idcresp.htm>> accessed 10 September 2013.

⁹⁴ Dhanda (n 25) 445.

⁹⁵ 'Report of the Fifth Session of the Ad Hoc Committee on a Comprehensive and Integral Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities', (New York, 24 January – 4 February 2005)

accordance with the paradigmatic shift of the Convention, only a supported decision-making model was acceptable.⁹⁶ However, they acknowledged the merit of the approach suggested by Canada that the Convention should be silent on the issue of guardianship; thus neither endorse nor prohibit it.⁹⁷ The IDC, together with several States⁹⁸ and the EU, sought to break the deadlock by suggesting the wording now contained in Article 12(4),⁹⁹ which ‘attempted to combine some of the safeguards required for guardianship with some of the standards required for supported decision-making’.¹⁰⁰ Article 12(4)’s malleable construction allows ‘each person to see what they desired in the paragraph’.¹⁰¹ Thus, while embodying a commitment to supported decision-making, Article 12 can also be read as permissive of substituted decision-making subject to safeguards.

Despite this progress, the disability community’s battle was not over. The text of Article 12 was then introduced subject to a footnote providing that in Arabic, Chinese and Russian ‘legal capacity’ referred only to ‘capacity to have rights’ rather than ‘capacity to act’. This footnote effectively removed the potential of Article 12 by making the ability to exercise legal capacity determinate on the severity of intellectual impairment. It would have meant that the CRPD would enshrine the partiality – rather than the indivisibility – of human rights on an equal basis for all. Following huge consensus¹⁰² the Eighth Ad Hoc Committee deleted the footnote. This was a significant victory for the IDC. Nevertheless, the dangers of

UN Doc A/AC.265/2005/2, <<http://www.un.org/esa/socdev/enable/rights/ahc5reporte.htm>> accessed 10 September 2013.

⁹⁶ IDC (n 88).

⁹⁷ Dhanda, (n 29) 448.

⁹⁸ EU Position elaborated together with Canada, Australia, Norway, Costa Rica, USA and Liechtenstein.

⁹⁹ Seventh Session of the Ad Hoc Committee on a Comprehensive and Integral Convention on the Protection and Promotion on the Rights and Dignity of Persons with Disabilities, ‘Comments, Proposals and Amendments Submitted Electronically’ (*UN Enable*, 30 January 2007) <<http://www.un.org/esa/socdev/enable/rights/ahcstata12sevcomment.htm>> accessed 10 September 2013.

¹⁰⁰ Dhanda (n 29) 450.

¹⁰¹ *ibid.*

¹⁰² D MacKay, ‘Letter from the Chair of the Ad Hoc Committee’ (*UN Enable*, 20 November 2006) <<http://www.un.org/esa/socdev/enable/rights/ahc8chair29nov.htm>> accessed 10 September 2013.

rights-abusive guardianship still lurk for people with intellectual impairments in Arab countries. Twenty-two States, who collectively formed the 'Arab Group'¹⁰³ during drafting, submitted a letter to the Chairman of the Ad Hoc Committee outlining that they only agreed to the consensus of the CRPD on the proviso that 'legal capacity' is interpreted as 'capacity of rights and not the capacity to act' in line with their domestic legal systems.¹⁰⁴ This effectively means that these states recognise the capacity to *hold* rights, but *not* the capacity to *exercise* them. It is argued that the abstract recognition of a disabled person as an equal 'holder' of rights will make little improvement to the lives of disabled people if they do not also have the corresponding ability to *exercise* the rights that they hold on an equal basis. It is submitted that being given the title of 'holding equal rights to legal capacity' is entirely meaningless without the real-life ability to exercise that right through making one's own decisions and having them respected. The distinction drawn by the 'Arab group' of States between the *capacity* to *hold* rights and the *capacity to exercise* rights effectively robs Article 12 of any practical impact and is a significant blow for the transformative potential of Article 12 in these non-Western cultures.

Out of the drafting process emerged an extremely ambiguous provision. Questions include: what support is required under Article 12(3) to allow disabled people to exercise their legal capacity? How can methods of support be implemented? Is substituted decision-making ever permissible for severe intellectual impairment? If so, on what grounds? Are the safeguards in Article 12(4) only to ensure that the support provided in assisted decision-making does not, itself, become oppressive or does Article 12(4) really refer to the safeguards needed in the rare cases where substituted decision-making is required? For Minkowitz¹⁰⁵ and the World

¹⁰³ The 'Arab Group' consisted of the following states: Algeria, Bahrain, Comoros, Djibouti, Egypt, Iraq, Kuwait, Lebanon, Libyan Arab Jamahiriya, Mauritania, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syrian Arab Republic, Tunisia, United Arab Emirates and Yemen.

¹⁰⁴ Letter from the Permanent Representative of Iraq to the United Nations addressed to the Chairman, (*UN Enable*, 5 December 2006) <<http://www.un.org/esa/socdev/enable/rights/ahc8documents.htm>> accessed 10 September 2013.

¹⁰⁵ Tina Minkowitz, 'Abolishing Mental Health Laws to Comply with the Convention on the Rights of Persons with Disabilities' in Bernadette McSherry and Penelope Weller (eds), *Rethinking Rights-Based Mental Health Laws* (Hart

Network of Users and Survivors of Psychiatry (WNUSP),¹⁰⁶ who have first-hand experience of guardianship, Article 12 never permits substituted decision-making even in extreme cases like being in a coma.¹⁰⁷ However, other disability organisations feel Article 12 ‘permits the continued operation of guardianship-type systems’¹⁰⁸ subject to safeguards as a measure of last resort.¹⁰⁹ Several State Parties have made declarations on adopting the CRPD that they interpret Article 12 as permitting the continuation of substituted decision-making systems.¹¹⁰ More disturbingly, some reservations of Arab states outline that Article 12 refers only to capacity to hold rights not capacity to act.¹¹¹ Arguably, these reservations are ‘incompatible with the object and purpose’¹¹² of the Convention and therefore should not be acceptable.¹¹³ However, it remains to be seen how the CRPD Committee will respond; whether it will arm itself with the jurisdiction to pronounce upon the validity of reservations¹¹⁴ and what the effects of declarations of invalidity

Publishing 2010) 156 (particularly ft 29).

¹⁰⁶ WNUSP, ‘Implementation Manual...’ (n 35) 3, 6, 11.

¹⁰⁷ World Network of Users and Survivors of Psychiatry, ‘Supported vs Substituted Decision-Making: Submission to the Committee on the Rights of Persons with Disabilities Day of General Discussion on CRPD Article 12’ (*United Nations Office of the High Commissioner for Human Rights*, 21 October 2009) 1 <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 10 September 2013.

¹⁰⁸ New South Wales Disability Discrimination Legal Center Inc, ‘Submission: “Article 12 of the CRPD – The right to equal recognition before the law”’, (*United Nations Office of the High Commissioner for Human Rights*, September 2009) <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 10 September 2013.

¹⁰⁹ For an academic opinion which appears relatively accepting of guardianship measures see: Keys (n 49) 59–88.

¹¹⁰ United Nations Treaty Collection, ‘Declarations and Reservation to the UN CRPD’ (*United Nations*, 2013) <http://treaties.un.org/Pages/ViewDetails.aspx?mtdsg_no=IV-15&chapter=4&lang=en> accessed 10 September 2013. See the reservations made by Australia and Canada.

¹¹¹ *ibid*, see the reservations made by Egypt, Iran, and the Syrian Arab Republic.

¹¹² UN CRPD (n 1) Art 46(1).

¹¹³ Quinn, ‘An Ideas Paper’ (n 78) 20.

¹¹⁴ Gerard Quinn, ‘Resisting the ‘Temptation of Elegance’: Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?’ in Oddný Mjöll Arnardóttir and Gerard Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, (*International Studies in Human Rights* (vol 100) 2009) 233, 241–245.

might be.¹¹⁵

The paper now addresses how Article 12 can be interpreted to overcome its linguistic controversy, and move towards a progressive model of supported decision-making. If implemented effectively Article 12 can realise the aims of the CRPD to achieve greater respect for the autonomy, equality and inclusion of disabled people. However, if little effort is invested in establishing supported-decision making, and Article 12's ambiguity is used to legitimise the continuation of guardianship, the potential of the entire CRPD may be lost.

IV. ARTICLE 12 AS 'A LODESTAR FOR THE FUTURE' NOT A 'STRANGLEHOLD OF THE PAST'¹¹⁶

For Quinn¹¹⁷ Article 12 cuts to the heart of understandings of what it means to be human.¹¹⁸ For Quinn¹¹⁹ and Bach¹²⁰ the transformative potential of Article 12 is the opportunity it presents to redefine the criteria by which we traditionally ascribe personhood (and legal capacity as the vehicle by which individuals exercise their personhood¹²¹) in order to be more inclusive of disabled people.¹²² Traditional assessments of legal capacity have rested on various requirements presumed necessary for legal beings in Western liberal democracies. These include: 'autonomy' – conveying notions of an atomistic, self-serving being, making decisions free from external influences and social realities; 'rationality' – the ability to process

¹¹⁵ Quinn, 'An Ideas Paper' (n 78) 20.

¹¹⁶ Dhanda (n 29) 429.

¹¹⁷ Quinn, 'Personhood and Legal Capacity...' (n 28).

¹¹⁸ *ibid* 3.

¹¹⁹ *ibid* 6–14.

¹²⁰ Michael Bach, 'The Right to Legal Capacity under the UN Convention on the Rights of Persons with Disabilities: Key Concepts and Directions from Law Reform' (*Institute for Research and Development on Inclusion and Society*, 21 October 2009) 8–11 (Prepared for Inclusion International for the General Day of Discussion of the UN Committee on the Rights of Persons with Disabilities) <http://irisinstitute.files.wordpress.com/2012/01/the-right-to-legal-capacity-under-the-un-convention_cr.pdf> accessed 14 September 2013.

¹²¹ Quinn, 'Personhood and Legal Capacity...' (n 28) 10.

¹²² Bach, 'The Right to Legal Capacity... Key Concepts and Directions for Law Reform' (n 120) 7.

information, foresee the consequences of various choices and weigh them to arrive at a logical conclusion; and the ability to express and communicate those choices to third parties in ways which ensure they understand the substance of one's decision. However, these presumptions are 'demonstrably counterfactual'.¹²³ Humans are fundamentally relational beings who reason in light of their social, economic and interpersonal relationships.¹²⁴ People without impairments depend on the support and input of their loved-ones and social networks. The decision-making process cannot sensibly be removed from this context. Additionally, we do not reason in a rational manner.¹²⁵ Our idiosyncrasies, preferences and prejudices inform our decisions; indeed they may incline us to repeat the same mistakes. This freedom for error is fundamental to personhood. Similarly, non-disabled people rarely fully understand all the implications of consenting to complex medical treatments or financial transactions.¹²⁶ In holding people with intellectual impairments to these standards for legal capacity, society holds them to a standard not met by the non-disabled. This in itself is discrimination of the kind prohibited by the CRPD.¹²⁷

'The true revolution [of Article 12] lies in... "affording persons the support they may require in exercising their legal capacity."¹²⁸ As well as providing support for relatively functional individuals, Article 12(3) can go further. Even for people who appear unable to express a will or preference (including those in a coma), substituted decision-making should not be the default position.¹²⁹ Medical advances can detect preferences by reading the brain activity of individuals with 'locked-in' syndrome. A patient with locked-in syndrome is conscious of their environment and awake but cannot

¹²³ Quinn, 'Personhood and Legal Capacity...' (n 28) 8.

¹²⁴ See the feminist critique of liberalism in V Munro, *Law and Politics at the Perimeter: Re-evaluating Key Debates in Feminist Theory* (Hart Publishing 2007) chs 2 and 3. Also see, Julie Wallbank, Schazia Choudhry and Jonathan Herring 'Welfare, rights, care and gender in family law' in Julie Wallbank, Schazia Choudhry and Jonathan Herring (eds), *Rights, Gender and Family Law* (Routledge 2009) particularly 15-18.

¹²⁵ Quinn, 'Personhood and Legal Capacity...' (n 28) 8.

¹²⁶ Bach, 'The Right to Legal Capacity... Key Concepts and Directions for Law Reform' (n 120).

¹²⁷ UN CRPD (n 1) Art 5 - right to equality and non-discrimination.

¹²⁸ Quinn, 'Personhood and Legal Capacity...' (n 28) 14.

¹²⁹ *ibid* 16.

move or communicate due to paralysis of almost all the voluntary muscles in the body. Consequently, such individuals are completely capable of forming a will or preference and of making their own choices. However, they are entirely unable to communicate that choice. By reading their brain activity, it is possible to detect individuals preferences and respect their life decisions.

For Quinn, ‘we should never give up’ on the possibility of detecting a will or ‘kindling some kernel of preferences’¹³⁰ in disabled people. Bach suggests two inclusive approaches on which to base the test for legal capacity.¹³¹ Firstly, the expression of intention as human agency.¹³² Here the idea is that the actions of a disabled person are informed by their intentions. While the actions of the person may not be understandable to a third party (like a doctor), people with personal knowledge of the disabled person can re-describe the action as intentional. Thus it can be demonstrated that the disabled person’s behaviour ‘communicates an intention or will to do or not do something’.¹³³ The second approach is a ‘narrative construction’ of personal identity.¹³⁴ This refers to the ability of the disabled person or others around them to provide a coherent answer to the question – ‘who is the disabled person?’ – based on their ‘life story of values, aims needs and challenges’.¹³⁵ Through permitting a re-definition of personhood, Article 12 can remove prejudice against disabled people by promoting a more inclusive view of what it means to be human and to exercise rights.

V. SUPPORTS AND SAFEGUARDS?

The article now examines what supports are actually needed under Article 12(3) to allow disabled people to exercise legal capacity on an equal basis with others. ‘[W]e are still in very early days with respect to regimens of supported decision-making and it may take

¹³⁰ *ibid.*

¹³¹ Bach, ‘The Right to Legal Capacity... Key Concepts and Directions for Law Reform’ (n 120).

¹³² *ibid* 9.

¹³³ *ibid.*

¹³⁴ *ibid* 10–11.

¹³⁵ *ibid* 11.

time to fix on the right regulatory mix with the rights safeguards'.¹³⁶ Therefore, the suggestions of some leading academics will now be examined as well as a brief outline of various policies already underway in some progressive countries which have moved towards supported decision-making.

Initially, policies and law reform should assist people who do not require elaborate support to exercise their legal capacity. This necessitates the provision of communicative assistance¹³⁷ including Braille, tactile communication, multimedia, augmentive and alternative models of communication,¹³⁸ information assistance and translators.¹³⁹ Crucially, communicative training must be provided for professionals in situations where disabled people exercise their legal capacity:¹⁴⁰ thus for doctors, lawyers, bankers and courts.

For individuals with more profound impairments, Bach advocates 'support networks' consisting of 'small group[s] of individuals who are in personal relationship[s] with the disabled person], have personal knowledge about the person. . . who commit on a voluntary basis to assisting a person to make decisions, and have their decisions respected'.¹⁴¹ Networks should consist of a diverse range of relationships: family, friends and wider community figures to help the disabled person make decisions.¹⁴² The disabled person themselves designates who should perform the supportive role.¹⁴³ The individual's full legal capacity is protected 'if they can demonstrate to others their will and intent, [or] if their personhood can be articulated by others designated as sufficiently knowledgeable to understand a person's unique communication forms and life

¹³⁶ Quinn, 'Personhood and Legal Capacity. . .' (n 28) 20.

¹³⁷ UN CRPD (n 1) Art 21.

¹³⁸ *ibid* Art 2.

¹³⁹ Bach, 'Supported Decision Making Under Article 12. . . Questions and Challenges' (n 44) 8–9.

¹⁴⁰ Minkowitz, 'Abolishing Mental Health Laws. . .' (n 105) 161.

¹⁴¹ Bach, 'Supported Decision Making Under Article 12. . . Questions and Challenges' (n 44) 11.

¹⁴² For a visual representation of this see: Paradigm, 'Supported Decision-Making: A Guide for Supporters' (Paradigm, Birkenhead, 2007) 14–15, <[http://www.paradigm-uk.org/Resources/9/2/9/Supported%20Decision%20Making%20\(Final%20Online%20Version\).pdf](http://www.paradigm-uk.org/Resources/9/2/9/Supported%20Decision%20Making%20(Final%20Online%20Version).pdf)> accessed 10 September 2013.

¹⁴³ Bach, 'Supported Decision Making Under Article 12. . . Questions and Challenges' (n 44) 11.

history'.¹⁴⁴

A successful support network was seen in the Canadian case¹⁴⁵ of Justin Clark,¹⁴⁶ where the court found Mr Clark to be competent despite psychologist's tests proving he was incapable of making an adult decision. This occurred on the basis of the personal knowledge given by witnesses for Mr Clark who understood his history, his wishes and his method of communication. The interpretations of Mr Clark's support community allowed the judge to form a coherent narrative about who Mr Clark was and what he wanted, and as such to respect his decision to move out of the institution where he lived. Bach advocates legislative provisions¹⁴⁷ and building community infrastructures, including local agencies, to provide support and assistance to develop support-networks, along with a registration process for designated supporters to be considered legitimate in healthcare or financial decisions.¹⁴⁸ While support networks are positive, in reality, many people with intellectual impairments do not have the structures and familial relationships required (possibly due to institutionalisation). While Bach argues that these networks need to be developed, in the meantime substituted decision-making may be necessary subject to appropriate safeguards under Article 12(4). Bach's approach is admirable for demanding the abolition of plenary guardianship, and requiring that any substituted decision-making be time-limited, subject to review and removed as soon as the needed community supports are available allowing the reintroduction of supported decision-making.¹⁴⁹ In the UK, both KeyRing¹⁵⁰ and The Circles Network

¹⁴⁴ *ibid.*

¹⁴⁵ Canada has been at the forefront of the development of models of supported decision-making including support networks. See M Bach and L Kerzner 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity', (Prepared for the Law Commission of Ontario, October 2010) 32–37, 80–82, <<http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>> accessed 10 September 2013.

¹⁴⁶ *Clark v Clark* (1982), 40 OR (2d) (Co. Ct.) (Matheson J) cited in Bach, 'What does article 12 of the CRPD Require? Theoretical Starting points and questions/implications for law and policy' (n 66).

¹⁴⁷ Bach, 'Supported Decision Making Under Article 12... Questions and Challenges' (n 44) 13–14.

¹⁴⁸ *ibid* 11–13.

¹⁴⁹ *ibid* 15–17.

¹⁵⁰ KeyRing Registered Charity No1054234 'KeyRing Home' (*KeyRing National*

are developing circles of support and inclusive communities.¹⁵¹

Sweden has advanced legal and non-legal provisions for supported decision-making. PO-Skåne¹⁵² is an independent NGO providing personal ombudsmen to disabled people. Ombudsmen seek out marginalised people with psychosocial impairments such as the homeless and attempt to build a personal relationship of trust with the disabled person. Ombudsmen do not act on the authority of anyone but the disabled person themselves.¹⁵³ Additionally, Swedish legal provisions include the 'good man' (mentor) system,¹⁵⁴ under which the appointment of a mentor does not affect the civil rights of the disabled person. The mentor can only act with the consent of the person. Indeed the disabled person has legal remedies against a mentor who acts outside his authority or attempts a transaction which the disabled person could have consented to. Swedish law also provides for contact persons, personal assistants and escort persons¹⁵⁵ who accompany disabled people to take part in leisure and community activities, achieving greater social integration. Sweden's reforms 'deserve world-wide attention'¹⁵⁶ from states looking to introduce supported decision-making legislation in order to properly comply with their obligations under Article 12 of the CRPD.

2012 Research by the Fundamental Rights Agency (FRA)¹⁵⁷ high-

Office, 2013) <<http://www.keyring.org/home>> accessed 9 September 2013.

¹⁵¹ The Circles Network Registered Charity No 1043601 'Welcome to the Circles Network!' (*The Circles Network*, 2013) <http://www.circlesnetwork.org.uk/home.asp?slevel=0z&parent_id=1> accessed 9 September 2013.

¹⁵² P O-Skåne, 'Swedish user-run service with Personal Ombud (PO) for psychiatric patients' (*PO-Skåne*, 2013) <<http://www.po-skane.org/ombudsman-for-psychiatric-patients-30.php>> accessed 9 September 2013.

¹⁵³ For more information about the Swedish Personal Ombudsmen scheme see European Union Agency for Fundamental Rights 'Choice and control: the right to independent living, Experiences of persons with intellectual disabilities and persons with mental health problems' (Publications Office of the European Union 2012) 56.

¹⁵⁴ Stanley Herr, 'Self-Determination, Autonomy and Alternatives for Guardianship' in Stanley Herr, Lawrence Gostin and Harold Hongju Koh (eds), *The Human Rights of Persons with Intellectual Disabilities: Different but Equal* (OUP 2003) 433.

¹⁵⁵ *ibid* 436–438.

¹⁵⁶ *ibid* 437.

¹⁵⁷ European Union Agency for Fundamental Rights 'Choice and Control: the right to independent living, experiences of persons with intellectual disabilities

lighted the discrepancy in levels of support available in different countries.¹⁵⁸ However, the research noted the merit in the Swedish provisions of contact persons and personal assistants¹⁵⁹ and the UK and German systems of 'person centred support'.¹⁶⁰ Person-centred support occurs mainly through 'direct payments' and 'personal budgets'. Here disabled people control their own support budget and can decide who to employ, what hours the employee should work and how they should provide support. Disabled people receiving direct payments report 'greater self-determination and self-esteem'.¹⁶¹ The FRA also found support from NGOs, self-advocacy groups and peer support groups to be crucially important, particularly in relation to increasing political participation.¹⁶² While many disabled people stressed the importance of informal support provided by family and friends,¹⁶³ the report outlined the danger that families may curtail disabled people's choices¹⁶⁴ and be influenced by financial motivations to keep disabled people in the family home or subject to guardianship provisions in order to ensure the continued receipt of disability benefits which may be considered a form of additional income for the family.¹⁶⁵ This reality is a clear demonstration of the abuse disabled people may suffer under the guise of 'support'. It is vitally important that State Parties ensure the safeguards in Article 12(4) are interpreted as applying to whatever support is implemented under Article 12(3).

The best way to unlock the transformative potential of Article 12 is for State Parties to adopt a broad conception of personhood. Similarly, they must devote commitment, innovation and resources to developing models of assisted decision-making appropriate to their particular society. While an extensive comparative analysis of different state provisions lays far beyond the scope of this paper, it

and persons with mental health problems', (Publications Office of the European Union 2012, <http://fra.europa.eu/fraWebsite/attachments/FRA-2012-choice-and-control_EN.pdf> accessed 10 September 2013.

¹⁵⁸ *ibid* 21, 41–42.

¹⁵⁹ *ibid* 31.

¹⁶⁰ *ibid* 32, 55.

¹⁶¹ *ibid* 32.

¹⁶² *ibid* 34, 55.

¹⁶³ *ibid* 22, 57.

¹⁶⁴ *ibid* 35, 46, 60.

¹⁶⁵ *ibid* 23.

is important to note that the nature of each particular state's social welfare and assistance provisions will affect the extent to which supported decision-making can be implemented quickly and effectively. States like the United Kingdom, Sweden, Germany and Canada, which already have progressive social provisions, will be able to meet the requirements of supported decision-making under Article 12 far more easily than States that provide less fully for disabled people. In less economically-developed countries like Somalia and Nigeria, disabled people remain stigmatised and may be seen as shameful. In these areas disabled people are dependent on their immediate family for assistance and care. In the unlikely event that any State assistance is available, it remains heavily centred on institutionalisation rather than support.

Despite this difficult reality, all states must attempt to make progress towards implementing supported decision-making within their domestic context. States should undertake a constructive dialogue by drawing on the successes of reforms and pilot schemes adopted by different countries. Examples of good practice and effective models of supported decision-making should be shared between countries. This sharing of information between governments can be supported and facilitated by the disability rights community, who should encourage States to make the most of the CRPD Committee Days of General Discussion and the Conference of State Parties.¹⁶⁶ Given the international nature and common goals of the disability movement, this sharing of information and good practice is not an unrealistic prospect.¹⁶⁷ Article 12(3) should be interpreted as obliging State Parties to provide the support necessary for even those with very challenging intellectual impairments to exercise their legal capacity.¹⁶⁸ The Article 12(4) safeguards must be interpreted as applying to the support provided under Article 12(3) in order to ensure that supported decision-making does not, itself, become a form of oppression for people with intellectual impairments.

Minkowitz argues that *any* substituted decision-making is un-

¹⁶⁶ UN CRPD (n 1) Art 40.

¹⁶⁷ Indeed, International Cooperation is also a requirement of the CRPD itself under Art 23, particularly 23(b).

¹⁶⁸ Quinn, 'Personhood and Legal Capacity...' (n 28) 16.

acceptable, and given the potential dangers of guardianship, this argument has some merit. Nevertheless, Quinn is correct to point out that characterising decisions made for someone in a coma as simply very high levels of support, risks ‘stretching fictions beyond the point of credulity’.¹⁶⁹ Arguably, Article 12(4) does permit a limited role for substituted decision-making. However, this must be an absolute last resort, be limited to individual decisions, and subject to probing independent review. Plenary guardianship systems which equate impairment with incapacity must be abolished. If Article 12(4) were interpreted as permitting the continuation of these systems, it would ‘swallow the paradigm shift’¹⁷⁰ of the Convention towards respecting the autonomy and equal rights of disabled people.

VI. IMPLEMENTATION

The aims in Art.3 of the CRPD will only be realised to the extent that State Parties make a meaningful commitment to implement the CRPD’s provisions effectively. We must resist the ‘temptation of elegance’;¹⁷¹ the assumption that words alone will bring the changes necessary to achieve greater substantive equality for disabled people. Quinn warns that States cannot be ‘persuaded’ or ‘socialised’ towards compliance with the CRPD if Reservations have already deflected the Convention’s core obligations.¹⁷² This paper has already demonstrated the reality that several states have adopted problematic Reservations which seek to avoid implementing Article 12’s core obligation; to move away from substituted decision-making models and towards implementing methods of support which allow disabled people to exercise their legal capacity on an equal basis with others.

Implementing regimes of supported decision-making will demand significant resources, time and infrastructure.¹⁷³ This will undoubtedly be met with resistance by State Parties claiming the

¹⁶⁹ *ibid* 21.

¹⁷⁰ *ibid* 20.

¹⁷¹ Quinn, ‘Resisting the “Temptation of Elegance...”’ (n 114) 216.

¹⁷² *ibid* 220.

¹⁷³ Bach, ‘Supported Decision Making Under Article 12... Questions and Challenges’ (n 44) 15, 17.

well-exercised 'limited resources' defence. However, the cost of supported decision-making must be off-set against the current costs of guardianship¹⁷⁴ before this defence is acceptable.

Presuming State Parties provide adequate resources, how best should support be implemented in each individual society? Here again the CRPD's involvement of disabled people provides the light. Disabled people are best placed to develop strategies for overcoming exclusion because they actually experience barriers in everyday life. Under Art.4(3) State parties must 'consult with and actively involve'¹⁷⁵ disabled people and their organisations in the 'development and implementation of policies'¹⁷⁶ to implement the Convention, along with involvement in the national monitoring process.¹⁷⁷ Devising schemes of supported decision-making with the active involvement of persons with intellectual impairments will greatly increase their chances of success and efficiency as they are formulated by the people whom they affect and resource is not wasted on misguided paternalistic provisions. The very process of involvement removes societal barriers by increasing respect for the decision-making abilities of people with intellectual impairments. A great bulwark to the strength of Article 12 is that the disability rights community, who fought so hard for a model of supported decision-making, will likely continue to fight hard for the proper implementation of the provision. Five years since the introduction of the CRPD, Quinn notes that there appears to be some resistance by states to the proper implementation of supported decision-making under Article 12.¹⁷⁸ This is a concerning reality. However, there has been no ambivalence from the disability rights community regarding the importance of the proper implementation of Article 12. It is crucial that the current momentum of the disability rights movement is maintained so as to ensure that states are encouraged to properly implement supported decision-making

¹⁷⁴ Quinn, 'An Ideas Paper' (n 78) 18.

¹⁷⁵ UN CRPD (n 1) Art 4(3).

¹⁷⁶ *ibid.*

¹⁷⁷ *ibid* Art 33.

¹⁷⁸ Gerard Quinn, 'Rethinking Personhood: New Directions in Legal Capacity Law and Policy' (University of British Columbia Centre for Inclusion and Citizenship Conference, Vancouver, 29 April 2011) 4-5 <<http://cic.arts.ubc.ca/research-knowledge-exchange/supportive-decision-making.html>> accessed 10 September 2013.

in order to achieve real improvements in the day to day lives of disabled people. Article 12 is a highly aspirational provision which presents real challenges for states in implementing its provisions. Nevertheless, the potential benefits of supported decision-making to the lives of disabled people means that the fight for meaningful implementation must continue.

VII. CONCLUSION

This paper has demonstrated why the protection of legal capacity in Article 12 of the CRPD is so fundamental to achieving positive change for disabled people. The ability of disabled people to exercise their legal capacity is a pre-requisite for their access to *all* the other rights enshrined in the CRPD. In order to achieve consensus between State Parties during drafting, Article 12 adopted ambiguous wording allowing different parties to see what they wanted in the construction. This has permitted diametrically opposed interpretations of what Articles 12(3) and 12(4) actually require. Article 12(3) advocates a model of supported decision-making consistent with the general principles of the CRPD to increase respect for the autonomy and dignity of disabled people.¹⁷⁹ However, this paper has demonstrated the danger that Article 12(4) could be interpreted as permitting the continuation of guardianship-style systems. Similarly, this paper expressed concern over Reservations to the Convention which undermine the transformative potential of Article 12 by restricting its meaning to that of ‘capacity for rights’ and not ‘capacity to act’. The disability rights community must continue its efforts to ensure that states interpret Article 12 progressively and omit the ambiguous language inherent within Article 12 which could undermine the aims of the entire Convention.

Article 12 provides the opportunity to adopt a broader conception of personhood which is more inclusive of disabled people and more reflective of the varied ways in which human beings reason. As we are still in the early stages of developing assisted decision-making models, this paper has not advanced an opinion regarding which methods of supported decision-making are most effective. Instead, it outlined the merit of some suggested approaches along

¹⁷⁹ UN CPRD (n 1) Art 3(a).

with the successes of some programmes already underway. This paper advocates a process of constructive dialogue between countries in order to better develop flexible and diverse methods of supported decision-making. While there may be limited scope for substituted decision-making under Article 12(4), this should be considered an absolute last resort, subject to stringent independent review, and should apply for the shortest possible time.

Ensuring effective implementation will be challenging. Nevertheless the involvement of disabled people means policies are informed by the first-hand experience of barriers and as such have the greatest chance of success. Involvement itself will demonstrate the decision-making abilities of disabled people and will reaffirm their right to have their legal capacity respected. Implementing supported decision-making will take commitment and resources. However, this may be proportional in order to rectify the massive disadvantages historically suffered by people with intellectual impairments. Through providing supported decision-making, respect and understanding of disabled people's abilities will increase. This benefits society at large as the community becomes a more diverse environment through embracing human difference. It is suggested that training programmes should to be provided to society as a whole. Doctors, lawyers, teachers, landlords and service providers interact with disabled people who are exercising their legal capacity in the real-life context. These members of the community must be educated to respect methods of supported decision-making. Only by learning to appreciate the rights and capabilities of disabled people will society reach a position in which disabled people can exercise their legal capacity on an equal basis with others. Recent Fundamental Rights Agency research reveals that much remains to be done before we reach a position of full inclusion.¹⁸⁰ Disabled people still feel their lives are characterised by 'a general lack of power and opportunity'.¹⁸¹ However, when disabled people's rights to self-determine are respected 'they undergo a form of liberation'.¹⁸² When Article 12 is implemented progressively

¹⁸⁰ European Union Agency for Fundamental Rights 'Choice and Control...' (n 157) 68–70.

¹⁸¹ *ibid* 8.

¹⁸² *ibid* 8, 11.

and adequate support is available, disabled people realise: 'the autonomy and freedom such measures brought to their lives' and the, 'inclusion and participat[ion] in community life that opened up to them'.¹⁸³

In conclusion, the future looks promising for disabled people gaining greater respect for their equal rights to self-determination. The European Court of Human Rights in *Stanev v Bulgaria*¹⁸⁴ recently acknowledged the CRPD's requirement to give disabled people 'as much legal autonomy as possible'.¹⁸⁵ The difficulties inherent in the wording and implementation of Article 12 can be overcome by State Parties making a strong commitment to move towards supported decision-making. Article 12 *must* be interpreted and implemented in a progressive manner and be read in accordance with the spirit and principles of the CRPD. If, with the pressure and momentum generated by the disability movement, this can be achieved, Article 12 can be considered the biggest driver for positive change in the entire Convention. It could truly be the way forward in the move towards full inclusion for disabled people.

¹⁸³ *ibid* 69.

¹⁸⁴ *Stanev v Bulgaria* App no 36760/06 (ECHR, 17 January 2012).

¹⁸⁵ *ibid* [244].