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International Journal of Mental Health and Capacity Law

Articles and Comment

Participation in Research and the CRPD

You Can't Go Outside: Involuntary Hospitalisation and Access to the Outdoors in Health Care

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Case Notes and Reviews

Case Note: N v Romania (Appn no 59152/08, 28 November 2017

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[2019] IJMHCL pages 1-78

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Editorial Board

The International Journal of Mental Health and Capacity Law is a peer reviewed open access journal devoted to the intersection between law, mental health and mental capacity. It builds on the well-reputed Journal of Mental Health Law, with a revised name to reflect its wider focus. It also follows the desire of its predecessor to combine academic articles and commentary with material that is designed to be used by practitioners – lawyers, and medical or social work professionals – in these nuanced areas.

The Editors are keen to receive academic articles, both shorter ones of around 5000 words and longer ones of up to 12,000 words; and practice points, case notes and reports of research of around 5000 words. Submissions should be made via the Journal's website - http://journals.northumbria.ac.uk/index.php/IJMHMCL/index - and comply with the directions given there as to process. Manuscripts should comply either with the Oxford University Standard for Citation of Legal Authorities (http://www.law.ox.ac.uk/publications/oscola.php) or the APA Referencing Style Guide. If you use footnotes, we encourage short footnotes.

Submissions must be original, properly reference any third party material and comply with any copyright limitations. Any possible conflicts of interest must be identified. If an article reflects original research involving human participants, a statement is required that relevant ethical requirements have been met, including an indication as to which body gave ethical approval for the research and the relevant reference number.

All submissions will be peer-reviewed by a double blind peer review process before being accepted for publication; naturally, there will be a process whereby an article may be accepted subject to minor or more major amendments being made. We will endeavour to provide feedback as to why any rejected submission has been rejected.

Contents

Page

Editorial

Kris Gledhill……..……2

Articles and Comment

Participation in Research and the CRPD
Anna Nilsson and Linus Broström……...……..……...3

You Can't Go Outside: Involuntary Hospitalization and Access to the Outdoors in Health Care
Julia Murphy…….……...……..…26

An Audit of Documentation relating to Decision-Making Capacity at an Old Age Psychiatric Hospital in England
Dr Sarah Amy Jones, Dr Bushra Azam, Dr Kevin Morgan, Dr Navjot Ahluwalia….……49

Case Note and Reviews

Case Note: N v Romania (Application No 59152/08, Decision of 28 November 2017
Alex Ruck Keene…….61

Book Review: The UN Convention on the Rights of Persons with Disabilities: A Comparative Analysis of the Role of Courts (Edited by Lisa Waddington and Anna Lawson) (OUP 2018)
Alex Ruck Keene…….70

Book Review: The UN Convention on the Rights of Persons with Disabilities: A Commentary (Edited by Ilias Banketas, Michael Ashley Stein and Dimitris Anastasiou) (OUP 2018)
Alex Ruck Keene……..76

Articles and pieces in this issue have been edited by:
Dr Tim Exworthy, Professor Kris Gledhill, Professor Penelope Weller, Dr Daniel Wang and Dr Darius Whelan.

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Hal (Zhan) Brinton

EDITORIAL

The variety of authors for this issue reflects what was hoped for when the Journal was renamed and relaunched, namely a mixture of articles done from different perspectives. The IJMHCL is, naturally, a legal journal: hence the word "Law" at the end of the title. But that law operates in a field that is necessarily multi-disciplinary – involving medical, nursing, psychology and social work professionals, supplemented by many others, from paramedics to occupational therapists. In addition, it involves interactions with multiple other areas of law and policy, including policing, criminal justice and prisons. Moreover, the operation of the law can be studied from many perspectives, including the vital voice of those who have experience of being "treated" by the system.

The three articles in this issue do not represent all the parameters of interest to the Journal, but have been put together from a mélange of perspectives. The first article is by academics in law and medical ethics and discusses the question of research participation by persons with disabilities; the second is written from a nursing perspective and reviews the question of the right of access to the outside during confinement in a psychiatric setting; and the third is an audit of medical practice in assessing capacity. Completing the issue are a case note and two book reviews have been produced by an author who combines being a legal practitioner, trainer and academic. There is interaction with the human rights framework in most of the pieces, most particularly the Convention on the Rights of Persons with Disabilities 2006 and the European Convention on Human Rights 1950.

This issue has involved significant collaboration: various people have taken editorial roles in relation to the various articles; in addition, we have the important contribution of our peer reviewers. Most importantly, we have people willing to put in the effort to write pieces that we can consider and, if all goes well, publish in our free-to-access journal, hoping to assist the debate in the important area we cover. I hope you find some value from the effort that many have put in to the production of this issue.

Kris Gledhill

PARTICIPATION IN RESEARCH AND THE CRPD

ANNA NILSSON AND LINUS BROSTRÖM*

ABSTRACT

This article discusses the implications of the United Nations' Convention on the Rights of Persons with Disabilities ("CRPD") for domestic policies on research involving persons with disabilities, including those with limited decision-making abilities. It starts with an examination of the protection the Convention affords to persons with disabilities against being enrolled in research projects, and argues that it does offer some such protection, but that the precise extent of this protection depends on conceptual and other matters that are not easily resolved by straightforward treaty interpretation. The article then proceeds with an analysis of whether the CRPD includes a right to participate in research projects on an equal basis with others. It argues that there are good reasons to interpret the CRPD to include such a right and explores its normative content. The article describes how the prohibition on discrimination delineates the scope for lawful exclusion of persons with disabilities in research studies and illustrates how discrimination analysis can be used to distinguish lawful practices from unlawful ones. It stops short, however, of drawing general conclusions about when exclusion is prohibited by the CRPD, arguing that this will depend on unresolved issues about the correct interpretation of the Convention's right to legal capacity, and on an analysis of the rights and interests at stake in any given situation.

I. INTRODUCTION

Human subjects research,[1] in various fields, is clearly important to societal progress. For such research to be possible, individuals obviously have to be provided with opportunities to participate in it. At the same time, participation is not always without risks or burdens. It is against a background of cases of serious harm to, and exploitation of, research subjects[2] that international treaties, declarations and guidelines on research on human subjects have been developed.[3] This fact helps to explain the focus on the *protection* of research participants in these documents, and the central role played by the requirement of free and informed consent.[4] Protection is secured in part by provisions regarding the risks and burdens of research (assessment, monitoring, minimization, acceptability, etc). The requirement of consent is intended to ensure that research participants understand the risks and burdens involved in a project and that they and are nonetheless willing to take part in it. To this end, article 7 of the

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[1] That is, research involving human beings as research subjects and/or research participants.

[2] The term "research subject" is still extensively used, not the least in codes of research ethics. Often, but not always, "research participant" may be more appropriate. In this paper both terms will be used, with no substantive distinction intended unless otherwise indicated.

[3] See e.g. the discussion leading to the prohibition of scientific and medical experimentation without consent (Article 7 ICCPR) in Annotations on the Text of the Draft International Covenants on Human Rights [UN Doc A/2929]A/2929, Ch. VI, para. 14. [1 July 1955]

[4] Teresa Iacono and Rachel Carling-Jenkins, 'The Human Rights Context for Ethical Requirements for Involving People with Intellectual Disability in Medical Research' (2012) 56 (11) Journal of Intellectual Disability Research, 1124-5, [1122].

International Covenant on Civil and Political Rights ("ICCPR") prescribes that "no one shall be subjected without his free consent to medical or scientific experimentation".[5] The Convention on Human Rights and Biomedicine (Oviedo Convention)[6] and its Additional Protocol concerning Biomedical Research (Protocol on Biomedical Research)[7] clarify that participation in research presupposes that the individual has been provided with appropriate information as to the purpose and nature of the intervention, as well as its consequences and risks.[8] They further state that research on persons lacking the ability to make free and informed decisions is only permitted if certain special safeguards are met.[9] The Declaration of Helsinki (DoH), developed by the World Medical Association and having in many contexts acquired the status of soft-law, incorporates similar standards.[10]

As indicated by the research governance just mentioned, ethical concerns have predominantly been raised about medical (or biomedical) research, and the regulatory safeguards put in place still relate, for the most part, only to those kinds of research. It is well-known, however, that ethically unacceptable or controversial research has been conducted outside of medicine, too. Quite a few studies in psychology, for instance, have elicited fear, anxiety, stress, embarrassment and similar effects at levels that cannot be considered innocuous, and have typically been conducted without fully informed consent.[11] In sociology, anthropology and, again, psychology, various studies involving covert (sometimes participatory) observation have been conducted, where the privacy and reasonable expectations of research subjects have been violated in ways that could be questioned from an ethical perspective.[12] And "field experiments" in economics, where researchers test what effects various manipulations of people's resources have on their acquisition and use of utilities they arguably need, have also raised ethical concerns.[13] Accordingly, some legal instruments are broader in scope and, as reflected in the occasional dissatisfaction with the codification of ethical concerns in

[5] International Covenant on Civil and Political Rights (United Nations [UN]) 999 UNTS 171, UN Doc A/6316, UN Doc A/RES/2200(XXI), Annex, UN Reg No I-14668, [Signed] 16th Dec 1966; [Entered into Force] 23rd Mar 1976.

[6] Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (Council of Europe) ETS No 164, 2137 UNTS 171, UNTS Reg No I-37266 [Opened For Signature] 4th Apr 1997; [Entered into Force] 1st Dec 1999.

[7] (Council of Europe) CETS No 195 [Signed] 25th Jan 2005; [Entered into Force] 1st Sep 2007.

[8] Oviedo Convention, Article 15, and Protocol on Biomedical Research, Article 13.

[9] Oviedo Convention, Article 15, and Protocol on Biomedical Research, Article 17.

[10] World Medical Association, Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects (adopted June 1964, last revised 2013) paras. 26 and 28.

[11]The Milgram obedience experiment probably being the most well-known one. Stanley Milgram, 'Behavioral Study of Obedience' (1963) 67 Journal of Abnormal and Social Psychology 371. But see e.g. Allan J. Kimmel, *Ethical Issues in Behavioral Research: Basic and Applied Perspectives*, 2nd ed. (Blackwell, 2007), ch. 3-4, for more examples.

[12] Laud Humphrey's infamous study of sexual encounters between males in public restrooms, so called "tearooms", in the 1960s is a case in point. Laud Humphreys*, Tearoom Trade: A Study of Homosexual Encounters in Public Places* (Duckworth, 1970). Other examples are addressed in e.g. Brian Schrag, 'Piercing the Veil: Ethical Issues in Ethnographic Research' (2009) 15 (2) Science and Engineering Ethics 135-60; and Kimmel (fn 11 above), ch. 5. For an overview of the many ethical (and methodological) challenges with participant observation, see Thomas J. Roulet et al., 'Reconsidering the Value of Covert Research: The Role of Ambiguous Consent in Participant Observation' (2017) 20 (3) Organizational Research Methods 487-517.

[13] See e.g. Megan Blomfield, 'Ethics in Economics: Lessons from Human Subjects Research' (2012) 5 (1) Erasmus Journal for Philosophy and Economics, 24-44.

research[14], other fields of research have increasingly had to adjust their practices to protective standards similar to those which researchers in medicine have to abide by. For example, Swedish legislation on research ethics[15] applies not only to medical or biomedical research. It covers all research involving physical interventions, attempts to influence participants (physically or mentally), obvious risks of participants coming to harm (physically or mentally), or the processing of "special categories of" personal data (as defined by the EU General Data Protection Regulation).[16] And while not legally binding, many influential ethics codes recognize the risk of harm and exploitation in those other fields as well, and include specific guidelines aimed to safeguard against various kinds of wrongdoing towards participants.[17]

In 2008, the CRPD came into force.[18] This treaty aims to ensure the full and equal enjoyment of human rights by persons with disabilities,[19] and although it incorporates provisions on the need to protect persons with disabilities from exploitation and harm, other interests are arguably at the forefront of it. These include respect for individual autonomy and participation and inclusion in the community.

Aims

In this article, we discuss some of the implications of the CRPD for domestic policies on research involving adult persons with disabilities, in particular persons with psychosocial, intellectual and cognitive disabilities, including impaired decision-making ability.[20] Such policies could, of course, pertain to research on the subjects' impairments, but they may just as often concern research unrelated to these impairments.

Our aim is to assess the extent to which the CRPD grants persons with disabilities (a) a right to participate in research and; (b) a right to protection against research enrolment. This assessment is timely and important. For one thing, the routine exclusion of certain groups from research projects obviously introduces a significant risk that many of the specific circumstances under which these groups live their lives remain under-

[14] See e.g. Will C. van den Hoonaard and Ann Hamilton (eds.), *The Ethics Rupture* (University of Toronto Press, 2016).
[15] Swedish Act concerning the Ethical Review of Research Involving Humans (SFS 2003:460).
[16] Regulation (EU) 2016/679 [2016] OJ L119/1. The Swedish Act concerning the Ethical Review of Research Involving Humans (fn 15), § 13 requires that, in all of these cases, ethics review is mandatory and in the former three kinds of research, informed consent is required by all adult research participants capable of providing it.
[17] See e.g. The British Psychological Society, 'Code of Human Research Ethics' (2014); American Psychological Association, 'Ethical Principles of Psychologists and Code of Conduct' (amended 2010 and 2016); section 8, American Sociological Association, 'Code of Ethics' (2018), Association of Social Anthropologists of the UK; and the Commonwealth, 'Ethical Guidelines for Good Research Practice' (2011), and the British Society of Criminology, 'Statement of Ethics for Researchers' (2015), section 4.
[18] Convention on the Rights of Persons with Disabilities, (United Nations [UN]) 2515 UNTS 3, UN Doc A/RES/61/106, Annex, GAOR 61st Session Supp 49, 65 [Adopted] 13th Dec 2006; [Opened for Signature] 30th Mar 2007; [Entered into Force] 3rd May 2008.
[19] CRPD, article 1.
[20] The CRPD does not define disability or any sub-categories thereof, and terms like "mental", "psychosocial", "intellectual" and "cognitive" disabilities are used to refer to slightly different categories of people in human rights law scholarship. We adopt a broad understanding of the relevant terms, recognizing that there may be a certain an overlap between these categories and that persons with multiple impairments can fall under more than one of them.

investigated, limiting the development of new and improved services tailored to meet their needs.[21] States party to the CRPD would then not fulfil their treaty obligations, and, more generally, it goes against the call from representatives of the disability movement for increased respect for personal choices.[22] On the other hand, the treaty's unequivocal condemnation of non-consensual experimentation on human beings reflects an ambition not to undo the hard-won protections of research subjects against harm and exploitation.[23]

Now, the CRPD arguably has implications not only for whether persons with disabilities have a right to participate or not participate in research, but also for states parties' policies on what kinds of research ought to be facilitated, and how, from a methodological standpoint, this research ought to be conducted. For example, there has been discussion within disability research about the value and prospects of participatory research designs.[24] This and similar interesting issues, however, lie beyond of the scope of the present paper.

Outline

The paper proceeds as follows: in Section 2, we ask what protection the CRPD provides for persons with disabilities against enrolment in research. Such protection is afforded by the Convention – explicitly, and sometimes implicitly – but its scope, we shall maintain, hinges on as yet unresolved issues about, inter alia, what counts as valid consent, and on the interpretation of (arguably vague) terms such as "experimentation", "integrity" and "exploitation".

Section 3 discusses the extent to which the CRPD includes a right to participate in research. It contends that while several of the Convention's articles presuppose that persons with disabilities participate in research, they fall short of actually granting a right to such participation. We also argue, however, that the right to equal protection and benefit of the law guaranteed by article 5 amounts to a right to participate in research on an equal basis with others.

Section 4 adds to the preceding and subsequent analysis by considering some of the potential reasons – legitimate or not – why researchers may decline to include persons

[21] The need to conduct research on issues that are important for marginalized groups have been discussed in relation to the right to enjoy the benefits of scientific progress included in the International Covenant on Economic, Social and Cultural Rights, (United Nations [UN]) 993 UNTS 3, CTS 1976/46, S Exec Doc D, 95-2 (1978), GAOR 21st Session Supp 16, 49, UN Doc A/6316, UN Doc A/RES/21/2200, [Adopted] 16th Dec 1966; [Signed] 16th Dec 1966; [Entered Into Force] 3rd Jan 1976; Article 15.1(b). See e.g. Human Rights Council, 'Report of the Special Rapporteur in the field of cultural rights, Farida Shaheed: The right to enjoy the benefits of scientific progress and its applications', A/HRC/20/26, paras. 15, 31, 43-44, (14 May 2012). The Committee on the Economic, Social and Cultural Rights is currently developing a general comment on article 15 that will presumably clarify the scope of states' obligations on this point.

[22] See e.g. Inclusion International, 'Independent but not Alone: A Global Report on the Right to Decide' (2014), World Network of Users and Survivors of Psychiatry (WNUSP); and Center for the Human Rights of Users and Survivors of Psychiatry (CHRUSP) 'Response to Draft General Comment on Article 12' (28 February 2014): wnusp.wordpress.com/advocacy/legal-capacity/ [accessed 14 January 2020].

[23] CRPD, article 15.

[24] See e.g. Mark Priestley, Lisa Waddington and Carlotta Bessozic, 'Towards an Agenda for Disability Research in Europe: Learning from Disabled People's Organisations' (2010) 25 (6) Disability & Society 731-47.

with disabilities in their research, and Section 5 explains how discrimination analysis can be used to distinguish lawful exclusion of persons with disabilities from research studies from discriminatory practices violating the CRPD. Here we argue that a proper discrimination analysis will involve balancing many different considerations, and that analyses will need, ultimately, to be made on a case by case basis. We end, in Section 6, with some concluding remarks.

II. CRPD AND THE RIGHT TO PROTECTION AGAINST RESEARCH ENROLMENT

Several provisions of the CRPD protect persons with disabilities from enrolment in research that is unethical or that they do not wish to participate in. Article 15 (Freedom from torture or cruel, inhuman or degrading treatment or punishment) prohibits cruel, inhuman and degrading treatment in general and medical and scientific experimentation without the free consent of the person concerned in particular. Article 17 (Protecting the integrity of the person) includes a right to respect for the integrity of the person and article 16 (Freedom from exploitation, violence and abuse) obliges states parties to take action to protect persons with disabilities from exploitation and abuse. These provisions target different kinds of misconduct. Article 15 deals with the most flagrant offences. It is modelled on article 7 of the ICCPR, and it is clear from the negotiation records of the CRPD that the drafters foresaw that it would be interpreted in light of the meaning the corresponding article had acquired in the ICCPR.[25]

Under the ICCPR, the prohibition of medical and scientific experimentation without consent has generated relatively little discussion. Rather than referring to a specific methodology, the term "experimentation" arguably denotes trying something out for the purpose of generating new knowledge. Hence, in the context of medicine, it serves to distinguish medical experimentation (or research) from medical treatment, which aims to improve the health of the person concerned.[26] The article makes a distinction between medical and (other) scientific experimentation. What research practices (*non*-medical) scientific experimentation covers is not clear from the text or the preparatory works. Manfred Nowak's commentary suggests, however, that essentially two types of malpractice are at issue: research on human subjects without consent, and research that causes significant harm to individuals or exposes them to great risks.[27] This clearly includes experiments of the kind carried out in the concentration camps during the Nazi regime, for example,[28] but the prohibition goes further; Nowak suggests that research on humans which leads to mutilation or other severe physical and mental suffering are impermissible, and other authors have interpreted the ICCPR in a similar vein.[29]

Precisely how the line should be drawn between research practices which infringe article

[25] Daily Summaries of the Fifth Session of the Ad Hoc Committee related to article 11 Freedom from torture or cruel, inhuman or degrading treatment or punishment (28 January 2005), morning session, see recorded statements by Chile, the Russian Federation and the Coordinator.
[26] Cf. Manfred Nowak, *U.N. Covenant on Civil and Political Rights: CCPR Commentary*, 2nd rev ed. (N.P. Engel, 2005), 190.
[27] Ibid., 190-191.
[28] The *travaux préparatoires* to the ICCPR confirms that the drafters' primary intention was to take a firm stand against the abhorrent experiments of totalitarian regimes conducted during World War II. General Assembly (fn 3 above) Ch. VI, para. 14.
[29] Nowak (fn 26 above), 191; and Sarah Joseph and Melissa Castan, *The international Covenant on Civil and Political Rights: Cases, Materials and Commentary*, 3rd ed. (OUP, 2013), [146].

15 of the CRPD and research practices which do not violate this provision is unclear. Arguably, low risk studies that only cause slight psychological distress to their participants do not constitute 'experimentation' or 'inhuman or degrading treatment' in the specific senses these terms have in international human rights law, even if such studies are undertaken without proper consent from the persons concerned. But the point at which research interventions become invasive or harmful enough to be covered by article 15 may be difficult to determine. From a legal point of view, this issue may not be very important since practices that do not fall within the protective scope of article 15 might nevertheless be prohibited by CRPD article 17, which stipulates that a person with disabilities has "a right to respect for his or her physical and mental integrity on an equal basis with others". Questions can be raised about the scope of article 17 as well, of course; the treaty text provides no information that helps us to decide what kinds of research project interfere with a person's integrity. There is little doubt, however, that research involving some form of physical intervention, such as taking a blood sample or undergoing a physical examination, falls within the scope of article 17.[30] Arguably, studies in which participants are asked to disclose sensitive information about their private lives or are observed in clearly private settings would also fall within the scope of this article.[31]

It may be that some research studies are prohibited by the CRPD because they violate article 16. To what extent the latter article could be used to safeguard persons with disabilities against unethical research enrolment depends in part on its relationship to articles 15 and 17. The main issue here is whether article 16 offers protection which is independent of that offered by these other articles; that is, whether there could be exploitation or abuse in research, in the sense assumed by article 16, without there also being cruel, inhuman or degrading treatment, *or* a violation of a person's integrity. Just how strong protection article 16 offers, in this context, obviously also hinges on the extent to which persons with disabilities are seen as vulnerable to exploitation or abuse. That persons with disabilities are more vulnerable than others, all else being equal, is uncontroversial in the context of the CRPD.[32] Precisely how vulnerable remains, however, an open question, and depends in part on one's views on the *sources* of such vulnerability; in particular, on the extent to which impairments and various social factors, respectively, contribute to it.[33] It also depends on one's views on the "dignity of risk"[34]

[30] Cf. European Court of Human Rights, *Y.F. v. Turkey*, appn 24209/94, 22 July 2003, 39 EHRR 34, paras 33-36. The case concerned a gynaecological examination without consent. The Court held that a person's body concerns the most intimate aspect of "private life", a concept which covers the physical and psychological integrity of a person. Thus, a compulsory medical intervention, even if it is of minor importance, constitutes an interference which must be justified to comply with the European Convention on Human Rights.

[31] It can be discussed whether research projects involving the processing of data from medical records or population-based registries only interfere with the protection of integrity in article 17 or also contravene the protection of privacy in article 22.2 of the CRPD. In human rights law, a clear distinction between the rights to respect for integrity and to privacy is not always upheld.

[32] This position has, however, been challenged in other theoretical and political contexts. The pitfalls of identifying especially "vulnerable groups" are for example brought to the fore by so called vulnerability theory. See e.g. Martha Albertson Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (2008) 20 (1) Yale Journal of Law and Feminism, 1-25.

[33] See for example Amanda Keeling, 'Article 16: Freedom from Exploitation, Violence and Abuse' in Ilias Bantekas, Michael Ashley Stein and Dimitris Anastasiou (eds.) *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018), 475ff.

[34] Piers Gooding, 'Supported Decision-Making: A Rights-Based Disability Concept and its Implications for

in relation to exploitation; that is, whether concerns about overprotection of persons with disabilities should be seen as limiting the applicability of article 16.

Taken together, the right not to be subjected to medical and scientific experimentation without consent, the right to equal respect for integrity and privacy, and states parties' obligation to prevent exploitation and abuse, on one level means that persons with disabilities benefit from the same protection against inclusion in unethical research as others. Nothing in the treaty text of the CRPD, or in the *travaux préparatoires*, suggests that these articles are intended to provide persons with disabilities with stronger (or weaker) protection from malpractice within the field of research than that afforded to persons generally. Thus, for example, persons with disabilities, just like everyone else, are protected against clinical research that could have been carried out on animals, that involves risks that are disproportionate to the potential benefits of the study, and that has not been approved by a research ethics committee.[35] And, as already mentioned, persons with disabilities, like everybody else, must be protected from research enrolment without their free and informed consent.[36] The fact the drafters appeared to aim for equal protection in these regards also means, however, that where research subjects are considered to have some particular vulnerability (situational or of another kind) additional safeguards may need to be put in place.[37] For example, and as just mentioned, the "strength" and concrete implications of the protection offered by article 16 depends on what we may legitimately assume about disabled persons' vulnerability to exploitation in the research context; which is a matter for continued discussion. In the next subsection, we shall also address article 12's take on equal protection when it comes to informed consent.

Finally, complementing the specific safeguards in articles 15-17, the general prohibition of discrimination in article 5 (Equality and non-discrimination) protects against discriminatory inclusion of persons with disabilities in research studies. For example, to selectively enroll persons with intellectual disabilities in a potentially harmful or burdensome nutrition study for reasons related to researchers' convenience is not only wrong because it may expose the research participants to unacceptable risks, or risks that they may find difficult to assess. It also concentrates the harms and burdens of such research to persons with disabilities in a discriminatory manner. One could also imagine cases where articles 15-17 may not come into play, but where the prohibition of discrimination in article 5 nonetheless applies; cases, for example, where selective inclusion of persons with disabilities in a study will reinforce public prejudice against this group, and may cause stigma.

Mental Health Law' (2013) 20 (3) Psychiatry, Psychology and Law 431, 435f.

[35] Cf. Oviedo Convention, Article 16, and its Protocol on Biomedical Research, Articles 5-7, and DoH, paras. 16 and 23.

[36] Cf. Oviedo Convention, Article 16(v), and its Protocol on Biomedical Research, Article 14, and DoH, para. 25.

[37] Cf. UNESCO, Universal Declaration on Bioethics and Human Rights, 33 C/Res 74; [Adopted] 19th Oct 2005, Article 8 (UDBHR); and DoH, para. 19. Examples of persons considered to be in need of additional safeguards include: prisoners and others deprived of their liberty; pregnant women; economically disadvantaged groups and persons suffering from ailments for which there is no satisfactory standard treatment. See Protocol on Biomedical Research, articles 12, 18 and 20, its explanatory report 'Explanatory Report to the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research', Strasbourg, 25 January 2005, para. 69.

A. Protection against enrolment without consent

As explained above, participation in research involving at least some kind of interference with integrity requires the free and informed agreement of the individuals concerned. What constitutes valid consent to research is not defined in the treaty text of the CRPD.[38] The negotiation records indicate that the appropriate formulation of the consent requirement was discussed during the drafting procedure, and that the phrase "free and informed consent" was chosen because it has an accepted meaning within human rights law.[39] In other human rights instruments covering participation in medical research, consent to such participation implies an agreement to take part in a particular research project that was obtained without threats or improper inducements and after disclosure of the aim of the project and the possible risks and benefits involved. In the European context, this understanding of consent is codified in the (legally binding) Oviedo Convention and its Protocol on Biomedical Research.[40] At the global level, it is embodied in the (not legally binding) UNESCO Declaration on Bioethics and Human Rights (UDBHR) and in bioethical declarations and guidelines developed by medical professionals and bioethicists, such as the DoH and the CIOMS guidelines.[41] These documents further clarify that research participants should be informed of their rights, in particular the right to withdraw consent at any time without reprisals.[42] Information should be provided in a comprehensible format to research participants.[43] Before obtaining consent, researchers must also ensure that research subjects have understood the information provided,[44] and in cases of doubt about an individual's ability to understand the relevant information, arrangements must be in place to verify whether or not the person has such ability.[45] Similar standards covering other fields of research can be found in various ethical guidelines.[46]

Notably, many codes distinguish between persons who are able to provide consent and those who are not. Where persons considered to fall within the latter category are

[38] References to consent occur in several provisions of the treaty, i.e. in article 15 in relation to medical and scientific experimentation, in article 25(d) with regard to provision of health care and in article 23.1(a) in relation to marriage. None of these provisions, however, define the term.

[39] General Assembly, 'Report of the Coordinator to the Ad Hoc Committee at its fifth session', Annex II to the Fifth Session Report of the Ad Hoc Committee, 25 February 2005, A/AC.265/2005/2, para. 39 and Daily Summaries of the Fifth Session (fn 25) recorded statements by the Russian Federation, New Zealand, Jordan, Australia, Luxembourg (on behalf of the EU), the Coordinator and the Office of the High Commissioner for Human Rights.

[40] Oviedo Convention, Articles 5, 15 and16(iv), and its Protocol concerning Biomedical Research, Articles 12-14. It should be noted that the Convention is ratified by 29 of the 47 Council of Europe Member States and that its Protocol is ratified by 11 States only.

[41] UDBHR, Article 6.2. See also DoH, paras. 25-26, and International Ethical Guidelines for Health-related Research Involving Humans, prepared by Council for International Organizations of Medical Sciences (CIOMS) in collaboration with the World Health Organization (WHO), guideline 9 (CIOMS guidelines).

[42] UDBHR, Article 6.2, Oviedo Convention, Article 5 and 16(iv-v), and its Protocol on Biomedical Research, Article 13.1 and 13.3, DoH, para 26, and CIOMS guidelines, guideline 9.

[43] UDBHR, Article 6.2, Protocol on Biomedical Research, Article 13.1, DoH, para. 26, and CIOMS guidelines, commentary to guideline 9.

[44] DoH, para. 26 and CIOMS guidelines, commentary to guideline 9.

[45] Protocol on Biomedical Research, Article 14.3 and CIOMS guidelines, commentary to guideline 16.

[46] Cf. The British Psychological Society, 'Code of Human Research Ethics' (fn 17 above), section 4, American Psychological Association (fn 17), 'Ethical Principles of Psychologists and Code of Conduct' (amended 2010 and 2016), section 8, and American Sociological Association, 'Code of Ethics' (fn 17), section 11.

concerned, these instruments permits exceptions to the rule that consent to research must be given by the research subject him- or herself. Persons who cannot consent may be enrolled in research projects if certain criteria are met. These are, roughly: the project has the potential to directly benefit the research subject; research of comparable effectiveness cannot be carried out on individuals capable of giving consent; and authorization has been given by a suitable third party (i.e. a legal representative or an authority).[47] In addition, potential research subjects lacking the ability to consent must nevertheless be informed about the research and what participation involves, so that they are involved as much as possible in the decision-making procedure. Also, the person must not object to participation.[48] Many clinical research projects cannot be expected to produce direct health benefits for the participants, so it follows from the above that persons who cannot provide free and informed consent should as a rule be excluded from such projects. There is one exception to this rule, however, as enrolment is permitted if the project aims to benefit other persons with the same disease, disorder or condition and the research involves minimal risks and burdens for those involved.[49]

The CRPD does not include standards at this level of detail, and questions about research participation received little attention during its negotiation.[50] It is possible to interpret the CRPD in light of the above standards, and to construe it so that it allows for the enrolment of persons with limited decision-making skills if and only if the criteria outlined above are met; and certainly this approach has been taken by some states parties to the CRPD in their interpretative declarations.[51] It is not entirely convincing, however. The protection package included in the Oviedo Convention, the DoH and several other codes is based on two assumptions: that some people – as a result of, for example, an impairment or a disease – lack the abilities necessary to provide *legally valid* consent to research, and that authorisation by a *third party* can compensate for such inability.[52]

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[47] UDBHR, Article 7(b), Oviedo Convention, Article 17.1(ii-1v), Protocol on Biomedical Research, Article 15.1(i-iii) and DoH, para. 28. Similar requirements are incorporated in the CIOMS guidelines, guideline 16, and national regulations, such as the Swedish Act Concerning the Ethical Review of Research Involving Humans (fn 15 above) §§ 20-22.

[48] UDBHR, Article 7(b), Oviedo Convention, Article 17.1(v), Protocol on Biomedical Research, Article 15.1(v) and DoH, para. 29.

[49] Oviedo Convention, Article 17.2, and Protocol on Biomedical Research, Article 15.2. UDBHR includes a similar limitation (in Article 7(b)), as does the DoH (paras. 28 and 30). A critical discussion of this provision can be found in Mats Johansson and Linus Broström, 'Does Peer Benefit Justify Research on Incompetent Individuals? The Same-population Condition in Codes of Research Ethics' (2012) 15 (3) Medicine, Health Care and Philosophy 287-94.

[50] The legitimacy of systems such as those envisaged in the Oviedo Convention was briefly discussed by a few states during the seventh session and then as part of a much broader discussion concerning the legitimacy of health interventions without the consent of the person concerned. Daily Summaries of the Seventh Session of the Ad Hoc Committee (19 January 2006), e.g. recorded statements by Norway and Yemen.

[51] France and the Netherlands have made interpretative declarations to the CRPD stating that they interpret the CRPD to permit enrolment of persons who are not able to consent in biomedical research if such enrolment is authorised by their representative or an authority or body provided and after the other protective measures included in human rights instruments have been undertaken. Full declarations available at: treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=iv-15&chapter=4&lang=en [accessed 14 January 2020]

[52] See e.g. Oviedo Convention, Article 17.1(iv), and its explanatory report 'The Explanatory Report to the Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine' Oviedo, 4 April 1997,

These assumptions are difficult to square with article 12 of the CRPD (Equal recognition before the law), at least under some influential interpretations of this article. Article 12.2 protects the right of persons with disabilities to enjoy legal capacity (i.e. to make decisions and have them respected by the domestic legal order) on an equal basis with others in "all aspects of life". The treaty text does not specify what this means in relation to persons with diminished capacity for understanding and reasoning, but the Committee on the Rights of Persons with Disabilities (CRPD Committee) has insisted that the possession of certain decision-making abilities is not a prerequisite of the right to enjoy legal capacity under the CRPD.[53] Article 12.3 of the Convention does oblige states to ensure that persons with disabilities have access to the *support* they may require in exercising their legal capacity. Nothing in the treaty text, however, appears to imply that states parties are permitted to disqualify decisions made without such support. Accordingly, the Committee submits that article 12.2 obliges states to recognize the choices of persons with disabilities as legally valid also in situations where there is doubt about an individual's ability to understand and weigh the relevant information and to appreciate the consequences of his or her decision.[54]

While this interpretation can be contested, it certainly harmonises with the CRPD's emphasis, in article 3, on respect for autonomy and individual self-determination. Applying this line of argument to the subject matter discussed here, the implication is that consent to research that would not have qualified as sufficiently informed under, for example, the Oviedo Convention and the DoH, is legally valid under the CRPD. Clearly, if this is correct, the CRPD affords weaker protection against research enrolment than those other instruments in this respect. Moreover, the CRPD contains no specific rules limiting the scope for research enrolment of persons who cannot provide legally valid consent. Whereas the Oviedo Convention, the DoH, and several other codes prohibit research involving those with certain intellectual or cognitive disabilities whenever the relevant study could be conducted with those with no disabilities instead, the CRPD does not. Likewise, whilst those codes of research ethics limit the participation of a person who lacks the ability to consent to situations where he or she may directly benefit or is not exposed to more than minimal risks and burdens, the CRPD contains no such additional requirements for research participants with impaired decision-making ability. This is another respect, then, in which the CRPD affords weaker protection against research enrolment for persons with cognitive and intellectual disabilities. With the exception of situations where discrimination, exploitation or abuse is involved, the CRPD treaty text, for example, provides no rules preventing persons with disabilities who (with or without support) do not understand what's at stake from participating in risky research. In part this may be explained by the fact that the CRPD has a broad scope and is less specific on matters concerning research ethics, but it is also in line with the CRPD Committee's refusal to hold some people to lack legal capacity.

B. Protection through legal representation

An intriguing question is whether the CRPD is compatible with domestic systems in which

paras. 41, 43 and 105. See also the explanatory report to the Protocol on Biomedical Research (fn 37) paras. 69 and 85, and DoH para. 28 and 30.

[53] CRPD Committee, *'General comment No. 1: Art 12: Equal recognition before the law'*, adopted 11 April 2014, CRPD/GC/1, paras. 13-15.

[54] Ibid.

a third party, often called a "legal representative", is mandated to decide on participation in research by persons who are believed to lack decision-making skills and who do not oppose such participation.[55] The treaty text offers no clear-cut answer to this question; it neither authorises nor prohibits such systems *per se*. As alluded to above, the debate over the correct interpretation of the CRPD on matters concerning legal capacity is ongoing. According to the CRPD Committee, the Convention prescribes that all forms of scientific and medical research on persons with disabilities must be based on the consent of those concerned, and argues that "such consent cannot be given via substituted decision-making".[56] In using the phrase "substituted decision-making", the Committee is referring to systems in which legal capacity is removed from the potential research participant and transferred to a third party who has not been selected (or at least accepted) by the person concerned, or in which a third party is authorised to make decisions based on what is believed to be in the potential participant's "objective best interest" as opposed to his or her "will and preferences".[57] It appears, then that the CRPD accepts support systems only where the third party is someone the potential participant has accepted or appointed (e.g. through power of attorney), and where the representative bases his or her decisions on the will and preferences of the person he or she represents.[58] As noted above, some state parties have interpreted the convention differently, however.[59]

The CRPD further prescribes that all measures relating to the exercise of legal capacity should provide for appropriate and effective safeguards to prevent abuse.[60] This includes regular review of the system by a competent, independent and impartial authority or judicial body to ensure that any "legal representatives" or support persons respect the rights, will and preferences of the person with disabilities, and that the relationship between that person and his or her representative/supporter is free of conflict of interest and undue influence.[61] Applied in the research context, this prohibits researchers from enrolling a person with disabilities in studies where this does not respect the latter's will and preferences. It also prevents persons with an interest in a research project from representing or supporting prospective research subjects in the same project. Furthermore, article 12.4 disqualifies unethical representatives who seek to achieve a certain outcome by means of threats, deception or manipulation.[62] Such safeguards are not explicitly mentioned in the previously discussed regulations focusing on research

[55] Persons who oppose participation in a research project must never be enrolled, regardless of their decision-making abilities, see fn 48 above.
[56] CRPD Committee, *'Concluding observations on the initial report of Montenegro'*, adopted 22 September 2017, CRPD/C/MNE/CO/1, paras 34-35, *'Concluding observations on the initial report of Costa Rica'*, adopted 12 May 2014, CRPD/C/CRI/CO/1, paras 31-32, and *'Concluding observations on the initial report of Italy'*, adopted 6 October 2016, CRPD/C/ITA/CO/1, paras 39-40.
[57] CRPD Committee, *'General comment No. 1'*, para. 27.
[58] In cases where the person's will and preferences cannot be determined, even though significant efforts have been made, the Committee prescribes that a decision is made based on the "best interpretation of will and preferences". Ibid., para 21.
[59] See fn 51 above. See also declarations made by Australia, Canada, Estonia, Ireland and Norway regarding the lawfulness so called substitute decision-making.
[60] CRPD, Article 12.4.
[61] Ibid.
[62] CRPD Committee, *'General comment No. 1'*, para. 22. Precisely where the line between due and undue influence is to be drawn in the context of the support paradigm is an intricate question Cf. Lucy Series, 'Relationships, Autonomy and Legal Capacity: Mental Capacity and Support Paradigms' (2015) 40 International Journal of Law and Psychiatry 80-91, [88].

ethics, for example the Oviedo convention or the DoH.[63]

Comparison of the support system advocated by the CRPD Committee and that foreseen in, for example, the Oviedo Convention reveals significant differences. Under the Oviedo Convention, third-party authorisation is a prerequisite of the inclusion of persons who wish to participate in a research project (or do not object to such participation) but are deemed to lack the ability to make free and informed decisions on the matter.[64] Without such authorisation, research on persons who cannot consent is unlawful. The CRPD contains no such authorisation requirement. Indeed, the support system envisaged by the CRPD Committee is a voluntary one, meaning that support must be made available to anyone who needs and wants it, but must never be imposed.[65] Another set of differences revolve around the fact that the Oviedo Convention accepts (but does not prescribe) domestic systems of legal representation in which the person or body responsible for authorizing research participation is not selected by individual concerned and may not even be accepted by him or her. It also accepts systems in which legal representatives are permitted to base their decisions on what they believe to be in the individual's best interest.[66] According to the CRPD Committee, such systems violate article 12 of the CRPD.[67] Last, but not least, the CRPD prescribes that support systems must be subject to regular review and strengthened by appropriate and effective safeguards.[68] The Oviedo Convention does not explicitly require monitoring of that kind.

The differences listed above affect the circumstances under which the respective systems prescribe, or accept, the exclusion, from research, of persons who lack ability to consent to that research. Inclusion is permissible under the CRPD in some situations where it would not be permitted under the safeguards imposed by most codes of research ethics, but it is also prohibited by the Convention under some circumstances where those codes would permit inclusion. Whether these differences, with respect to legal representation, imply that one of the systems provides stronger protection than the other will depend, in part, on what one believes prospective research subjects ought to be protected against. The primary purpose of the CRPD support system is to ensure that persons with disabilities are not enrolled in research studies or provided with certain legal representation when this can be said to conflict with their will and preferences. The systems endorsed by the Oviedo Convention, the DoH, etc. have a different focus, aiming to protect persons with limited decision-making abilities from harms, risks and burdens of research participation even in situations where the individual appears to be willing to bear these burdens. How well the systems meet their aims in practice will depend, of course, on empirical issues – issues including the availability of decision-making support and legal representation, and the quality of the services provided under the relevant arrangements.

Although it remains an open question whether a support system or a system of legal

[63] Protocol on Biomedical Research, Article 12, however, obliges ethics committee to ensure that no undue influence is exerted on persons to participate in research.
[64] Oviedo Convention, Article 17(iv).
[65] CRPD Committee, *'General comment No. 1'*, paras. 18 and 29(b) and (g).
[66] The Oviedo Convention provide states with a fair amount of discretion when designing their systems in this regard. See the explanatory report to the Oviedo Convention (fn 52), para. 42.
[67] CRPD Committee, *'General comment No. 1'*, paras. 27, 29(b) and (g).
[68] CRPD, article 12.4.

representatives provides the most effective protection against enrolment in research studies, the discussion in Section 2.1 shows that many codes of research ethics impose stricter limits on research inclusion than those defined by the CRPD. On the other hand, the CRPD arguably provides persons with disabilities with a stronger right to contribute to research. Indeed, the CRPD Committee has expressed concern over the fact that some states parties have not taken appropriate action to ensure that persons with disabilities are permitted and enabled to consent to research.[69]

To summarise, the CRPD protects persons with disabilities against unethical research enrolment. Article 5 protects against discriminatory enrolment. In addition, articles 15-17 prohibit non-consensual experimentation, exploitative or abusive research practices, and studies that violate a person's integrity. The strength of this protection package depends on several factors, most notably on the interpretation of terms such as "experimentation", "exploitation" and "integrity". It also depends on how, in view of article 12, we conceptualise valid consent and on the design of the system for support or legal representation in place in the domestic context. The next section will discuss whether, and to what extent, the CRPD not only safeguards against involuntary enrolment, but creates an individual right to participate in research.

III. CRPD AND THE RIGHT TO PARTICIPATE IN RESEARCH

The first thing to note is that the Convention contains no explicit right to research participation. However, it sets out several rights and obligations which presuppose that persons with disabilities participate, in one way or another, in research. Article 31 (Statistics and data collection), for example, insists that states parties collect information, including statistical and research data, to enable the formulation of adequate policies giving effect to the CRPD. Compliance with that article will, at a minimum, involve the processing of data on persons with disabilities, but in many cases it will also require persons with disabilities to be personally engaged, observed and/or exposed to interventions, and the like. Article 4 (General obligations) requires states parties to undertake or promote research on universally designed goods and services and to develop accessible information and communications technologies.[70] Article 24 (Education) requires states to set up inclusive education systems that maximize the academic and social development of disabled pupils and students.[71] Similarly, articles 25 (Health), 26 (Habilitation and rehabilitation), and 27 (Work and employment) oblige states to ensure that persons with disabilities have equal access to health care services,[72] to comprehensive rehabilitation and habilitation programmes,[73] and to suitable vocational guidance and training programmes, respectively.[74] To meet these obligations, states will need to develop an understanding of how best to ensure inclusive teaching,

[69] CRPD Committee, 'Concluding observations on the initial report of Uganda', adopted 12 May 2016, CRPD/C/UGA/CO/1, para. 28 and 'Concluding observations on the initial report of Kenya', adopted 30 September 2015, CRPD/C/KEN/CO/1, paras. 29-30.
[70] CRPD, Articles 4.1 (f) and (g).
[71] CRPD, Article 24.1 and 24.2 (e).
[72] Article 25(a) and (b) obliges states parties to provide persons with disabilities with "*the same range, quality and standard* of free or affordable health care and programmes as provided to other persons" [our italics] and ensure that persons with disabilities have access to any health services they may need because of their impairment/ disability.
[73] CRPD, Article 26.1.
[74] CRPD, Article 27.1(d).

promote employment, secure equal access to adequate health interventions, etc., and there is little prospect of their doing so, with sufficient reliability, unless research involving persons with disabilities is conducted. Having said that, an obligation for states parties to conduct research on persons with disabilities will at most support a right for this group of persons to be involved in research: it does not ground any individual right.

Article 9 (Accessibility) also has implications for the right to research participation. While it does not grant persons with disabilities a right to such participation *per se*, it obliges states parties to take steps to remove obstacles to whatever participation opportunities there would otherwise be. For example, states parties are obliged to put in place appropriate measures ensuring that research studies will – when necessary, and to the extent possible – make information material accessible to persons with disabilities, so that this group will not be excluded as the result of insufficient accessibility efforts being made by the state. Moreover, failure to take reasonable action to accommodate impairment or disability-related needs in individual cases violates the prohibition of discrimination: article 2 (Definitions) makes it clear that the denial of reasonable accommodation is a form of discrimination akin to direct and indirect discrimination; and article 5 paragraph 3 obliges states to ensure that reasonable accommodation is provided whenever it is needed.[75]

Moreover, as has already been discussed, article 12.2 of the CRPD protects the right of persons with disabilities to exercise legal capacity on an equal basis with others. This includes the right to decide whether or not to participate in research; should an opportunity to be enrolled in a study present itself. Paragraph 3 entitles prospective research participants to the support they may need and want to express legally recognized consent. However, this provision does not imply a right to be invited to, or enrolled in, a particular research study; it merely ensures that whatever research opportunities are offered, the person with disabilities is to choose whether or not to take them. In the remainder of this section, however, we will argue that there are good reasons for interpreting the Convention to include, also, a stronger right – a right to participation in the development of new knowledge *on an equal basis with others*. This, if correct, implies that when research studies are being conducted they must be open to prospective participants with disabilities, if they are open to others.

A. The right to participate on an equal basis with others

Article 5 of the CRPD obliges states parties to ensure that persons with disabilities are entitled to equal protection and benefit of the law. To this end, states shall prohibit all discrimination on the basis of disability.[76] The Convention defines disability-based discrimination as follows:

> any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any

[75] Article 2 in CRPD defines reasonable accommodation as the "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms".
[76] CRPD, Article 5.2.

other field.[77]

A literal interpretation of this definition suggests that a practice must aim at, or have, a negative impact on the enjoyment or exercise of a human right in order for it to be discriminatory. As discussed above, the "right to participate in research" appears in neither the CRPD nor any other human rights treaty. This does not mean that the exclusion of persons with disabilities from research falls outside the scope of the Convention's protection against discrimination, however. Article 5 of the CRPD is modelled on article 26 of the ICCPR,[78] and since the late 1980s the Human Rights Committee has interpreted the latter as a freestanding prohibition on discriminatory domestic legislation and practices in any field regulated and protected by public authorities.[79] The CRPD Committee has affirmed that article 5 must be interpreted in the same vein.[80] In view of the purpose of the CRPD – which is to ensure that persons with disabilities enjoy the same level of protection of human rights as others – this seems reasonable.[81]

If it is assumed that article 5 of the CRPD applies to research participation, the question becomes: would the exclusion of persons with disabilities from research participation constitute discrimination as defined in article 2? The answer appears to be that it would, if two criteria are met. First, the relevant exclusion must be based on reasons that are related to disability/impairment.[82] The presence of a disability does not have to be the sole reason for exclusion, however. The prohibition of discrimination has been interpreted to cover also disadvantageous treatment based on reasons which appear to be neutral but have a disproportionate impact on persons with disabilities; this is often called indirect discrimination.[83] A situation where ostensibly disability-neutral legal requirements make the inclusion of those with disabilities so cumbersome or costly that researchers avoid enrolling such persons would be a case in point (more examples will be given in the next section).

Secondly, the exclusion must have a negative impact on those concerned.[84] It can, of course, be questioned whether exclusion from research participation harms or disadvantages those excluded. The main purpose of research, after all, is to generate

[77] CRPD, Article 2.

[78] The first two paragraphs of article 5 of the CRPD are almost a carbon copy of article 26 of the ICCPR.

[79] See e.g. Human Rights Committee, 'General comment No. 18: Non-discrimination', adopted 10 November 1989, HRI/GEN/1/Rev.9 (Vol. I), adopted 10 November 1989. In para. 12 the Committee states: "[a]rticle 26 does not merely duplicate the guarantee already provided for in article 2 but provides in itself an autonomous right. It prohibits discrimination in law or in fact in any field regulated and protected by public authorities. […] In other words, the application of the principle of non-discrimination contained in article 26 is not limited to those rights which are provided for in the Covenant."

[80] CRPD Committee, *'General comment No. 6 on equality and non-discrimination'*, adopted 26 April 2018, CRPD/C/GC/6, para. 13.

[81] Vienna Convention on the Law of Treaties (1969), 1155 UNTS 331 [Adopted] 23rd May 1969; [Opened for Signature] 23rd May 1969; [Entered into Force] 27th Jan 1980, article 31.1. This provision affirms that treaty-based norms are to be interpreted in accordance with the "ordinary meaning" of the terms "in their context and in the light of its object and purpose".

[82] In article 2 the CRPD defines discrimination as "any distinction, exclusion or restriction *on the basis of disability"* [our italics].

[83] CRPD Committee, *'General comment No. 6'* (fn 80), para. 18(b).

[84] Article 2 in the Convention speaks of state practice that "has the purpose or effect of *impairing or nullifying* the recognition, enjoyment or exercise […] of human rights and fundamental freedoms" [our italics].

new knowledge, not to promote the well-being or serve the interests of the individual participating in the study. Participating individuals devote time and effort to the projects in which they are involved, but those projects cannot be expected to yield any direct personal benefits for them, and from that perspective it may be more natural to think of research participation as, if anything, a burden. However, there are situations where enrolment in a study may offer the participant tangible benefits. For example, in medical research participants may be remunerated, receive superior health monitoring, learn more about their condition, and about ways to alleviate or cope with its negative effects, or receive some other "collateral" benefit. Participating in a clinical trial may also, on occasion, be the only way of gaining access to certain treatment, where no other therapeutic intervention is available or where the treatment being tested holds out some special promise. To participate in a pedagogical intervention study will sometimes be the only the way of getting access to a course taught with certain new and promising educational methods, and there might, for example, be no other way of being eligible for a particular program for occupational rehabilitation than to accept being enrolled in a research study of the effects of that program.

A less tangible benefit, but possibly just as important, is that persons with disabilities, like others, may have an interest in contributing to society's pursuit of knowledge, just as they may have an interest in other ways of discharging their (self-perceived) moral obligations towards others.[85] A fairly extensive corpus of literature suggests that participation in at least some kinds of research is indeed often based on altruistic considerations.[86] Even when this is not the case, however, persons with disabilities may have an interest in the opportunity to participate simply because others have this option. That is, whether or not research participation, or pulling one's weight as a member of society, can be regarded as a benefit, arrangements which deny disabled persons opportunities that others have are, in themselves, negative for persons with disabilities.

Finally, the exclusion of disabled persons from research for reasons related to disability/impairment may have wider deleterious effects: it could, for example, reinforce stereotypical images of persons with disabilities as people who are unable to make socially valued contributions to society, and eventually this may contribute to social exclusion.

If we accept that persons with disabilities may benefit from research participation, or at least from having that option, depriving persons with disabilities of an opportunity to participate in research can certainly be viewed as a disadvantage. The next question is whether such disability-related disadvantageous practices can be justified under the CRPD. The treaty text is silent on this matter. So are other human rights treaties

[85] Recent jurisprudence from the Court of Justice of the European Union could be interpreted to support this view. In a case concerning a French regulation banning blood donations by men who have had or currently have sexual relations with other men, the Court held that men covered by the ban were treated "less favourably" than male heterosexual donors. The regulation therefore discriminated among potential donors based on sexual orientation and needed to be justified to not violate the prohibition on discrimination. Court of Justice, *Léger v. Ministre des Affaires sociales, de la Santé et des Droits des femmes*, C-528/13, ECLI: EU:C:2015:288, paras. 49-51.

[86] For a few recent examples, including further references, see Jennifer s. Carrera et al., 'Research Altruism as Motivation for Participation in Community-centered Environmental Health Research' (2018) 196 Social Science & Medicine 175-81, and Deborah Goodman et al., 'Factors that Motivate Participation in Observational Genetic Cancer Research Studies' (2019) 9 (2) Open Journal of Epidemiology 156-72.

developed under the auspices of the UN. Still, these latter treaties have been interpreted so as not to outlaw every action which, strictly speaking, meets the definition of discrimination: practices pursuing a legitimate aim, based on "objective and reasonable criteria", do not violate the prohibition of discrimination they set down.[87] There are good arguments for the view that the CRPD's prohibition of disability discrimination leaves room for a similar possibility of justification. This would accord with the drafter's intentions and with the Convention's purpose of ensuring that persons with disabilities enjoy the same human rights protection as others, and no state party has so far challenged it.[88]

In Section 5 we will illustrate how argumentation about the legitimacy and lawfulness of research protocols that exclude persons with disabilities may play out.

IV. POTENTIAL REASONS FOR EXCLUSION

As a preliminary to the hands-on discrimination analysis to be presented in Section 5, it will be helpful to distinguish between different conceivable reasons why researchers, rightly or wrongly, may decide not to enrol persons with certain psychosocial, intellectual or cognitive disabilities in their studies. The rationale for such exclusions strongly bears on whether or not they can be justified, and hence their compliance with the prohibition on discrimination. Below, four types of rationale, or reason, are considered. In many cases, the exclusion of persons with disabilities for these reasons may well amount to discrimination in the sense prohibited by article 5. However, the goal of the discussion is not to determine whether any of the four reasons considered are discriminatory in this sense. It is rather to describe imaginary scenarios which add flesh to the general analysis of discrimination set out in Section 5.

A. Exclusion based on protection

Persons who might otherwise have been considered for inclusion in a research study could be excluded on grounds of protection. As has already been mentioned, key research ethics guidelines, declarations and conventions guarantee certain protections. Researchers could attempt to justify the exclusion of persons with disabilities by appealing to those safeguards. For example, a person with an intellectual disability may declare an interest in participating in a phase I drug trial, i.e. a trial designed to assess the safety of a drug in healthy volunteers. The person in question, it can be supposed, meets the general eligibility criteria for enrolment, with respect to age, sex, somatic health status, etc., but the researchers nevertheless decide not to include this person. Pointing to the fact a phase I trial involves risks, they determine that the person lacks the ability to provide informed consent and appeal to the prohibition against enrolling persons without decision-making capacity if the relevant research could be conducted with participants who are able to give consent.

[87] Anna Nilsson, 'Article 2: Definitions' in in Ilias Bantekas, Michael Ashley Stein and Dimitris Anastasiou (eds.) *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018), 75; and Rachele Cera, 'Article 5 [Equality and Non-Discrimination]' in Valentina Della Fina and Rachele Cera Giuseppe Palmisano (eds.) *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer, 2017), [160].

[88] Anna Nilsson, 'Objective and Reasonable? Scrutinising Compulsory Mental Health Interventions from a Non- discrimination Perspective' (2014) 14 (3) Human Rights Law Review 459-85, [463-4].

In another scenario, researchers are recruiting participants for an evacuation study, targeting persons with mid-stage Alzheimer's disease, and with the ultimate aim of designing and marking escape routes in a way adapted to the behaviour of this group and that of those with similar disabilities. In accordance with requirements in the standard codes of research ethics serving to protect research participants from tangible harm and exploitation, participants are enrolled with the consent of their loved-ones, who act as their legal representatives. However, those with no significant others – at all, or available – are excluded, again in line with the consideration not to include unrepresented persons without the ability to consent.[89] Alternatively, the researchers may instead wish to enrol the potential participants under a support paradigm, but note in a particular case that none of the persons that could be asked to provide the relevant support for the person with Alzheimer's is fit to fulfil that role.

B. Exclusion based on methodological concerns

Research is governed by various general scientific norms connected with its aim of generating sound results that can be trusted. Such norms guide researchers when they design their studies, and some of the methodological standards that have to be met relate, directly or indirectly, to participant selection. Researchers could, therefore, decide, on occasion, not to include persons with certain disabilities in order to guarantee the methodological quality of the research. For example, a subpopulation of those with psychosocial disabilities could be excluded if there are reasons to believe that this group runs a greater risk of dropping out from the study, since high attrition rates make it hard to obtain statistically significant results. Individuals could also be excluded on the basis that, with their level of cognitive impairment, they have poor prospects of fully following complex study instructions. Again, the chances of obtaining data which can be correctly interpreted may in some cases be judged slim. That may arise when a research interview would have to be conducted with the help of support (someone interpreting what the person with disabilities expresses). For that reason, or similar reasons, interview responses may be difficult for researchers to assess.

Presumably, many methodological challenges can be met with appropriate training and resources (cf. below), but the possibility of an ineliminable tension between the goals of inclusion and scientific quality cannot be ruled out a priori.

C. Exclusion based on perceived irrelevance to the research question

Researchers' choices to not include persons with a disability in their studies are sometimes best explained by the focus of their research questions. Researchers may be interested in doing human subject research on issues affecting groups which happen not to include persons with disabilities. For example, a study surveying the factors affecting the wellbeing of PhD students at top universities is unlikely to enrol those with significant cognitive disabilities. At times, however, failure to enrol persons with disabilities will be the result of ignorance about, or inattention to, the fact that such

[89] See e.g. the British Psychological Society, 'Code of Human Research Ethics' (fn 17), section 4, and Swedish Act concerning the Ethical Review of Research Involving Humans (fn 15), §22. Cf. also Oviedo Convention, Article 17.1(iv) and its Protocol on Biomedical Research, Article 15(iv).

persons are part of the population one is interested in – and that their experiences, needs, perspectives and so on, may be different from those that persons without disabilities have. These are cases where persons with disabilities may not be deliberately excluded, but where the researchers fail to see that considerations of representativeness dictate that such persons are included.

D. Exclusion based on limited resources

Finally, the involvement of persons with cognitive or psychosocial disabilities in research may be both time consuming and resource intensive, and researchers could for that reason decide to avoid it.[90] In particular, offering potential participants the special protection that their impairments call for may (be believed to) raise costs and/or slow down the project. Adapting and monitoring the consent procedure, finding individuals prepared and able to provide decision-making support, and making thorough risk assessments that take into consideration the specific impairments and situation of those being considered for enrolment, are some of the measures that may (be believed to) present a challenge for researchers with promised or expected deliverables, deadlines and limited project budgets. Any measures requiring extra training, on the part of researchers, will typically tax resources. Additional "hurdles" in the form of tougher scrutiny by research ethics committees may also need to be reckoned with.[91]

V. DISCRIMINATION ANALYSIS

In Section 3, it was argued that the CRPD gives persons with disabilities the right to participate in research on an equal basis with others. This obviously applies to all kinds of research conducted at public universities and other academic institutions. Indirectly, it also applies to research conducted in private settings. According to article 4.1(e), state parties must "take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise". This means that no researchers, public or private, are free to exclude persons with disabilities from research participation in discriminatory ways.[92]

In order to determine whether a concrete case of exclusion from research participation violates or complies with the CRPD, one must consider the reasons for exclusion (cf. section 4). All research that excludes persons with disabilities for disability-related reasons must serve legitimate aims and be based on objective and reasonable criteria to comply with the Convention.[93] Starting with the first of these conditions, the pursuit of a legitimate aim, it can be seen that in all of the imagined scenarios above researchers were motivated by legitimate aims. In the examples, the exclusions were intended to protect research subjects, to secure methodological quality, to pursue a particular research interest or to proceed on limited resources. All of these aims, in themselves, are compatible with the CRPD.

[90] As noted by Iacono and Carling-Jenkins (fn 4), researchers have complained about the over-regulation by ethics committees of research involving people with intellectual disabilities.
[91] Cf. Nancy A. Pachana et al., 'Can We Do Better? Researchers' Experiences with Ethical Review Boards on Projects with Later Life as a Focus' (2015) 43 (3) Journal of Alzheimer's Disease 701-7.
[92] Cf. CRPD Committee, *Bacher v. Austria*, Communication No. 26/2014, adopted 16 February 2018, CRPD/C/19/DR/26/2014, para. 9.3.
[93] Section 3.1.

For exclusion of prospective research participants to be based on "objective" criteria, such exclusion must be relevant to – typically by contributing to – the (legitimate) aim.[94] Exclusion decisions must not be based on ignorance or (negligently) mistaken assumptions about the excluded group. It would, for example, be discriminatory to exclude persons who are blind, or deaf, on the basis of prejudicial assumptions about the cognitive abilities of such persons. Whether a given research protocol contributes to the aims in question is essentially an empirical matter that can only be answered definitively in relation to a concrete case. There is, however, little doubt that the exclusions of persons with disabilities in the examples given above serve the relevant aims in one way or another. Preventing persons with intellectual disabilities from participating in a phase I drug trial will, of course, protect this group from the risks associated with such participation. The same is true for persons with mid-stage Alzheimer's disease who are excluded from research enrolment because they lack legal representation. And in situations where funding for support and accommodation is lacking, excluding persons with certain disabilities can indeed be a way to ensure the methodological quality of the study.

In addition to being (justifiably believed to be) instrumental to the achievement of legitimate aims, exclusions of persons with disabilities need to meet the criterion of reasonableness. This last step of the discrimination analysis serves to ensure that the practices under review are fair and do not produce consequences that are unduly burdensome for those affected.[95]

Judgements on reasonableness take several considerations into account. These include the importance of the interests at stake, and the positive and negative effects of the practice under review.[96] They also include the consideration of alternative ways to proceed meeting the same aims.[97] There is no basis for making unqualified general statements about whether excluding persons with disabilities from research is reasonable. But to illustrate how reasoning about the reasonableness of exclusion can unfold, let us consider the first example provided in previous section. This example involves the exclusion of a person with an intellectual disability from enrolment in a phase I drug trial because he or she is believed to lack the ability to consent. (Similar considerations apply to the other conceivable grounds for excluding persons with disabilities.) The primary interests at stake here are, on the one hand, the interest of those with disabilities in being protected from certain harms, and, on the other hand, the interest of the same people in being considered as prospective research subjects and allowed to make their own choices about whether or not to get involved. Both interests are important, and the reasonableness of the decision to exclude the individual from the study hinges, by and large, on its positive and negative effects in view of alternative ways to achieve the positive outcomes and mitigate the negative consequences.

[94] Anna Nilsson, *Minding Equality: Compulsory Mental Health Interventions and the CRPD* (PhD thesis, Faculty of Law, Lund University, Media Tryck, 2017), [80].
[95] Ibid., [81-85]. The UN treaty bodies have sometimes couched their reasoning about reasonableness in terms of "proportionality". See e.g. CRPD Committee, *H.M. v. Sweden*, Communication No. 3/2011, adopted 19 April 2012, CRPD/C/7/D/3/2011, paras. 8.2 and 8.8.
[96] Nilsson (fn 94) 81f.
[97] Ibid., 82.

As noted above, research protocols excluding any disabled person who does not fully understand the risks involved in research participation arguably protect those with disabilities from harms and burdens associated with research participation. A critical question here is whether a similar level of protection could be achieved by other means. One way to facilitate research participation without compromising the participant's interest in protection is to provide decision-making support. Indeed article 12.3 of the CRPD obliges state parties to ensure that persons with disabilities have access to such support. Whether various support mechanisms could effectively enable free and informed consent in all situations where an individual wishes to participate is, however, an empirical question, one which cannot be settled by stipulation. The development of support mechanisms to aid people in their decision-making has only recently begun and there are good reasons to be optimistic about the future. A growing body of literature discusses the prospects of providing such support in various situations where personal decisions are to be made.[98] But this is an area in which relatively little empirical research has been conducted, and it remains unclear whether the various forms of support being considered will meet the needs of all those currently being excluded from research participation for reasons of cognitive and mental impairment.

In situations where the support provided fails to give the potential participant an adequate understanding of what study participation will involve, we need to balance the costs and benefits of the decision (or policy) under consideration to determine its reasonableness. Turning first to the benefits of exclusion, people vary in their cognitive abilities and decision-making skills. The reasons against including a particular participant in a research study are arguably weightier in situations where he or she does not understand the risks involved, or overestimates the chances of gaining direct health (or other) benefits from the project, than they are in situations where the lack of understanding concerns more peripheral information. In addition, research projects differ in the risks and burdens to which they expose their participants. While it seems fair to exclude persons lacking certain decision-making abilities from high-risk projects, it may be unreasonable to exclude the same group from participation in low-risk, low-burden, studies where participants are, say, expected to answer a set of innocuous questions or will merely have a blood sample taken. The risk of instrumentalising those who do not fully understand what the research is about remains, of course, but the need for protection is arguably less in low-risk, low-burden studies than it is in studies that are more demanding for participants or expose them to more serious risks and burdens.

A closer evaluation of the costs of exclusion would also be necessary. It would be important, for example, to ask whether the relevant study may involve direct benefits for those enrolled. As the Oviedo Convention, its Protocol on Biomedical Research, and the DoH all suggest, it may be unreasonable to exclude persons who cannot consent to research participation from studies that have the potential to produce real and direct

[98] *Ex pluribus* Michael Bach and Lana Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity - Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice', prepared for the Law Commission of Ontario, 2010, 72ff and Piers Gooding, *A New Era for Mental Health Law and Policy: Supported Decision-Making and the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press, 2017), ch. 6.

health benefits to participants.[99] Other benefits could also be considered. People choose to participate in research for a range of reasons,[100] and whatever benefit a participant can be expected to obtain from his or her participation (clinical, psychological, educational or another sort), if this benefit could be significant, this too would have some bearing on the lawfulness of any exclusions. At the same time, it should be kept in mind that the main positive outcomes of research are not, in general, benefits to the research subjects, but rather benefits to science or society. Including persons with disabilities in research projects facilitates the development of technical aids and new services tailored to meet their needs. It also enables states to create more accessible and inclusive societies and thereby fulfil their treaty obligations under the CRPD.[101] The more important that aim is considered to be, the greater is the probability that leaving persons with disabilities out of research studies will be considered unlawful.

As the points above illustrate, judgements of reasonableness take a variety of considerations into account, among them: the availability of support enabling free and informed consent, the magnitude of the harms and burdens that the person may have to endure in the study, the tangible benefits that he or she may be deprived of if excluded, and the importance of the research project's contribution to society. The fact that it can be very difficult to determine whether the potential participant understands the risks to which he or she will be exposed in a particular research project, or whether a given set of support measures enables free and informed decisions to be made, adds to the complexity of the matter. Similarly, the difficulties involved in determining the probability of the harms, burdens and possible benefits of a particular research project add to the complexity of any assessment of these harms, burdens and benefits. When the different considerations are being balanced, the certainty, or reliability, with which all of these assessments has been made arguably also needs to be taken into account. Where, for example, estimates of the expected benefits of a particular project, or the probability of their occurrence, rest on uncertain data, this will reduce the weight of the reasons in favour of including persons who are unable to consent. Conversely, if such estimates rest on certain information, that will strengthen the case for inclusion.

To summarise, it is difficult, if not impossible, to provide a comprehensive answer to the question: under what circumstances can the exclusion of persons with disabilities from research participation be considered reasonable, and therefore lawful under the CRPD?

Judgements of reasonableness can only be reached in the context of a particular study and a particular group of prospective study participants – where the weight of the reasons for and against participation are balanced against each other. As already mentioned, while the CRPD grants persons with disabilities many different rights, some of which do relate to protection against research enrolment, taken as a whole it can indeed be read as guidance intended to curb, among other things, paternalistic policies and attitudes. That is why special emphasis is given in the Convention to such interests as individual autonomy, and participation and inclusion in the community. Even on that

[99] Oviedo Convention, Article 17.1, and its Protocol on Biomedical Research, Article 15.1. DoH para. 28. A similar argument could be made with regard to other forms of direct benefits such as access to a particular educational method or program for occupational rehabilitation, see section 3.1.
[100] See e.g. Michael C. Soule et al., 'Understanding Motivations to Participate in an Observational Research Study: Why Do Patients Enroll?' (2016) 55 (3) Social Work in Health Care 231-46.
[101] Section 3.

reading, however, it is far from clear that this translates into these interests having decisively greater weight in the balancing of reasons for and against research enrolment – that is something that would have to be argued on a case-by-case basis.

VI. CONCLUDING REMARKS

The nature and scope of the basic rules governing research-based knowledge production and the rights of those who participate in it are critical issues for every society. Such rules must ensure that important research is made possible. They must also safeguard against unethical research: research that is unnecessary, flawed in its design, exploitative, or such that its potential benefits do not compensate for the risk of harm it introduces. The rules also need to be consistent with general norms of fairness, and in particular non-discrimination. How to reconcile these demands is a recalcitrant issue that every society will have to deal with.

Sometimes explicitly, but in the main implicitly, the CRPD addresses all of the above demands. Article 15 outlaws medical and scientific experimentation without consent, and articles 5 and 16-17 prohibit research practices that are discriminatory, exploitative or violate research participants' integrity. As discussed above, the precise scope of this protection will remain unclear until there is agreement over what, in the CRPD, constitutes valid consent, and who can provide it.[102] What is more, the CRPD arguably grants a right for persons with disabilities to participate in research. There is an obligation on states parties to conduct research involving members of this group and a duty to ensure that prospective research participants with disabilities have access to adequate decision-making support.[103] In addition, the right to legal capacity gives persons with disabilities the right to decide whether or not to participate in research should an opportunity present itself.[104]

Last but not least, the prohibition of discrimination embedded in the Convention outlaws research protocols that exclude persons with disabilities unless such exclusion can be justified, and the necessary justification requires careful consideration of a number of interests and considerations, all of which need to be balanced.[105]

As a final note, researchers need to design CRPD-compliant non-discriminatory research protocols. Success in this endeavour will depend on further work on the implications of the CRPD for human subjects research. Additionally, codes of research ethics may need to be reworked, so as to better reflect the Convention's demand for equal treatment of those with and without disabilities while still achieving the codes' key aims, i.e. the facilitation of important research and safeguarding against harm and exploitation. This is no easy task. Understanding these challenges better, and how best to meet them, is a matter for further research.

[102] Section 2.2.
[103] Section 3 and CRPD, Article 12.3.
[104] CRPD, Article 12.2.
[105] Sections 3.1 and 5.

YOU CAN'T GO OUTSIDE: INVOLUNTARY HOSPITALIZATION AND ACCESS TO THE OUTDOORS IN HEALTH CARE

JULIA MURPHY*

ABSTRACT

This paper will explore the practice of withholding a person's access to the outdoors while under involuntary hospitalization, or civil commitment, in the province of Ontario, Canada. Following a question from the author's clinical practice, the paper asks: Are we denying mental health patients a right that is protected for prisoners?

An overview of the structure of the Canadian legal system and the role of international human rights law in local legislation is offered to situate lack of outdoor access under civil commitment in a broad legal context. The intention of legal and ethical positions described in human rights and mental health law will be considered in light of how these support or negate current practices in health care. Key issues of civil commitment will be defined. Law and policy governing outdoor access in other institutions such as prisons and detention centers will be outlined as a point of comparison.

The purpose of this paper is to serve as a guide to thinking through the issue of institutional confinement without access to the outdoors when a person's independent freedom of movement is compromised, legally or otherwise. Should there be future interest in challenging this practice, this paper will be useful as a primer for how to approach legislation and institutional policy.

Key words: Canadian legal system; Mental Health Act (1990); Ontario; Deprivation of liberty; Ultra vires; Human rights; Psychiatric nursing; Hospital design; Outdoor spaces; Fresh air; Patient rights; Civil commitment

I. INTRODUCTION

> *From behind panes of plexiglas, a man knocks at the sliding window. I open it. He looks down at his hands, one cradling the other, and begins to count out his rights. "One shower, one change of clothes, one hour of fresh air. As a prisoner, that is what I am entitled to." He has been a prisoner before, but that is not his designation here. We are in a general hospital, in an acute care psychiatric unit, and I am his nurse not his warden. I answer, "You are welcome to all the showers and changes of clothes you would like, but I can't let you outside."*
>
> - Vignette from the author's nursing practice -

Civil commitment is the involuntary confinement of a person to a hospital under the power of mental health legislation. Currently, in Ontario, Canada, the *Mental Health Act* (1990) (hereafter the MHA) permits involuntary hospitalization if a doctor determines that one of two alternative statements pursuant to section 20(1.1) and section 20(5), 'Conditions for involuntary admission,' are met. (On the ancillary Ministry of Health certificates, involuntary hospitalization is indicated under Box A criteria – the Serious Harm test – and involuntary treatment under Box B criteria (Queen's Printer for Ontario, 2000).) The MHA separates these two assessments. If a person is determined to be

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incapable of making decisions about their treatment due to their mental status, forced administration of psychiatric treatments are permitted under the Health Care Consent Act (1996) in conjunction with a substitute decision maker.) Under the statutory powers of the MHA, enactment of a certificate of involuntary admission by a doctor drastically alters a person's right to consent and suspends their freedom of movement. A certified patient cannot leave the hospital until the certificate expires or is lifted by their psychiatrist. Section 20(4) of the MHA explains that each certificate is time-limited and must be re-assessed at prescribed intervals.

Confinement on a locked mental health unit is recognized as a deprivation of liberty in that the MHA establishes minimum threshold criteria for civil commitment, so as to safeguard against abuses. Confinement is distinct, however, from 'restraint' in the terminology of the MHA and other bodies governing health care. 'Restraint' refers to an intervention "to prevent serious bodily harm to the person or another by the minimal use of force, mechanical or chemical means" – mechanical, like binding a person's wrists and ankles to a bed, or chemical, like administering a psychotropic medication to "intentionally inhibit a particular behaviour or movement" (MHA, Definitions, 1990). Restraints are interventions to protect safety, but they are openly the subject of debate, while confinement does not inspire similar contention or controversy.

In Ontario hospitals, a doctor's order is required to apply a restraint, but the recommendation to use a restraint is most often made by the nurse working directly with the patient. As such, the College of Nurses of Ontario (CNO) advises: "Restraints should be used only for the shortest time when prevention, de-escalation and crisis management strategies have failed to keep the individual and others safe" (Understanding Restraints, 2018). The Registered Nurses Association of Ontario (RNAO) developed a Clinical Best Practice Guideline entitled, *Promoting Safety: Alternative Approaches to the Use of Restraints,* in 2012 that articulates the concept of restraints as an intervention of last resort. What continues to be a challenge for inpatient mental health nurses is the limited resources available for meaningful alternatives to de-escalate and manage agitation, aggression, or threats of violence. An ethnographic study of restraint use in a Toronto hospital by Sandy Marangos-Frost and Donna Wells (2000) found nurses experienced an ethical dilemma when restraints were viewed to be "the best available option" in the situations in which they were used due to "the apparent lack of acceptable alternatives" as well as "unit factors" (366). Without concrete infrastructure to support alternatives, like an outdoor space, restraints continue to be used.

In addition to mechanical restraints placed upon a person's body, the CNO and RNAO describe 'environmental restraints' as controlling a person's mobility (CNO, 2018; RNAO, 2012: 19). In writ, the MHA does not authorize psychiatric facilities to detain or restrain an informal or voluntary patient, according to section 14. In practice, placement in a secure ward is the *de facto* disposition when a person is admitted for inpatient mental health care in Ontario. This is the case for both voluntary and involuntary admissions because inpatient mental health units are locked and are permitted only in hospitals designated by the Ministry of Health and Long-Term Care (MHOLTC) as Schedule 1 facilities (institutions where patients may be restrained if necessary according to the MHA.) There are 70 Schedule 1 facilities in Ontario, including forensic institutions for the treatment of those found Not Criminally Responsible for a crime due to a mental

disorder (MHOLTC Health Services in Your Community, 2012). Toronto, Ontario has 13 Schedule 1 facilities of which I have been to 7 - 2 had outdoor space for the general ward, none had outdoor access for their acute units (Personal experience.) A voluntary patient ostensibly has the right to exit the mental health unit, but in practice, the voluntary patient's right to exit the secure unit is mitigated by their physician's assessment of their safety. To leave the secure unit requires permission (the privilege of a "pass") and permission can be denied. If denied a pass, the voluntary patient can revoke their consent to hospitalization (opt for discharge against medical advice) or choose to stay inside the hospital and continue to receive treatment. Should the client meet criteria for involuntary admission at the time of their assessment for a pass and should the client opt to be discharged against medical advice, the physician can, of course, initiate a certificate of involuntary hospitalization.

According to the MHOLTC's communication group, there is no obligation for hospitals to provide secure outdoor space for patients (Personal Correspondence, September 26th, 2016).

> Ministry of Health and Long-Term Care does not have any policies or standards in place for design requirements. The board of directors of the hospital along with the architect they choose to hire determine the design of the facility;
>
> Depending on the lot of the facility, there may or may not be outdoor space available to allow involuntary patients to access the outdoors (Personal Correspondence, September 26th, 2016).

This means that access to a secure outdoor area is arbitrarily dependent on the hospital's design. Architectural constraints and the lack of legislation in Ontario on the issue of outdoor access have created conditions across the province that make confinement without outdoor access permissible in general hospitals. This is so routine in practice that I was challenged in the writing of this paper to qualify whether human beings have a right to fresh air at all. The secure unit is a form of environmental restraint in that the person's mobility is limited to the hospital unit, but with the distinction in the MHA between custody and restraint, and with more visceral practices, like wrist cuffs or chemicals, confinement is taken as a simple fact of inpatient mental health treatment, not as a deprivation. Nursing documentation practices also illustrate the conceptual distinction between restraint and confinement. When mechanical restraints are implemented in Ontario, nursing protocols are typically triggered to monitor the restrained person to ensure the person is fed, toileted and ambulated. There are medical rationales for these – the body's need to void and the risk of deep vein thrombosis due to the immobility imposed by mechanical restraints – as well as the legal imperative to document the sensible use and monitoring of restraints should a legal complaint arise. However, no such protocols exist to reflect health considerations when a person is admitted to a secure unit, like daily outdoor access for bone health or sleep regulation. In the absence of cues to consider confinement to a secure unit as different from an open unit, confinement seems benign rather than exceptional.

Confinement as a feature of mental health care has been under examined and normalized as a result. This could change. An amendment not-yet-in-force as of 2019 to the *Long-Term Care Homes Act* (2007) is notable because in section 3, 'Residents' Bill of Rights', restraint is related to confinement:

> 3.13
>
> Every resident has the right not to be restrained, except in the limited circumstances provided for under this Act and subject to the requirements provided for under this Act.
>
> Note:
>
> On a day to be named by proclamation of the Lieutenant Governor, paragraph 13 of subsection 3 (1) of the Act is amended by striking out "restrained" and substituting "restrained or confined". (See: 2017, c. 25, Sched. 5, s. 2 (2))

Positive strides in legislation have also been made for long-term involuntary patients in the wake of the landmark Ontario court case *PS v Ontario* (2014) that has opened "the door to a fuller recognition of the profound deprivation of liberty involved in civil commitments" by drawing comparison between provincial criminal Review Board jurisprudence and civil commitment Review Board jurisprudence (Grant & Carver, 2016: 999). Still, people in Ontario continue to be routinely deprived of outdoor access when admitted as an inpatient for mental health care, and, unfortunately, Ontario is not unique. A digital scan of all ten Canadian provinces' mental health acts using the search terms 'outdoor,' 'fresh air,' 'program,' 'access,' 'recreation' and 'privilege,' found that no province delineates outdoor access as an entitlement for involuntary patients. (Mental Health Act, Statutes of Nova Scotia 2004; Mental Health Care and Treatment Act, Statutes of Newfoundland 2006; Mental Health Act, Statutes of New Brunswick 1973; Mental Health Act, Statutes of Prince Edward Island 1994; An Act Respecting the Protection of Persons Whose Mental State Presents a Danger to Themselves or to Others, Statutes of Quebec 1997; The Mental Health Act, Statutes of Manitoba 1999; Mental Health Services Act, Statutes of Saskatchewan 1984; Mental Health Act, Statutes of Alberta 2000; and Mental Health Act, Statutes of British Columbia 1996).

> If we don't even appreciate that consumers and staff are both feeling locked in, we may not even think that we need to do something about it (Arya, 2011: 165).

Nurses do hear patients say they feel cooped up and caged in and nurses themselves express ambivalence about the plexiglas nursing station that is both a measure for occupational safety and glass-walled box (Arya, 2011). The patient's statement that opened this paper took the everyday practice of confinement to a mental health unit without daily access to the outdoors and snapped it into focus. It looked strange. I understood the medico-legal rationale for the patient's confinement on the basis of safety, both the patient's and that of the community, but the assertion that an hour of fresh air would be permitted in prison prompted me to question what legal and ethical grounds there are, if any, for withholding a person's access to the outdoors when confined under civil commitment. What specific legal protections should apply to people whose liberty is restricted by a locked ward? Are we denying mental health patients a right that is protected for prisoners in the jurisdiction of Ontario? Are there arguments to be made for secure settings to have secure outdoor areas for all patients?

METHODOLOGIES

To fully explore the strangeness of involuntary confinement without access to the outdoors in Ontario hospitals, this paper presents a close study of Canadian mental health law and criminal law, and a comparison of local legislation to international human rights law. Semi-structured interviews carried out for this project with both legal experts

and health care practitioners explore interpretations of legislation and perceptions of confinement in practice. Interviews received ethics clearance from York University and informed consent was obtained from interviewees at the research stage and for this publication. Identities of interviewees have been anonymised with aliases. They are: "Leonard," a provincial court judge; "Martin," a lawyer practicing in public interest environmental law; "John," a lawyer practicing in the area of criminal law on behalf of the Ministry of the Attorney General; and "Rose," a registered nurse working in mental health in Ontario.

This is not a dispassionate paper.

To situate myself, I work as a registered nurse in Ontario where my professional experience includes psychiatric settings and refugee primary care. I care about mental health and nursing and, like many others in my field, I struggle against parameters of practices that are not obviously therapeutic. I am of the mind that questions raised in clinical practice are important for nurses and health care providers to investigate. I also feel aware that sometimes it feels risky to talk about these questions outside of the nursing station. There is a fear of violating the responsibility to protect a client and their privacy or a sense of limited professional autonomy to safely question ethically challenging practices outside of the hierarchy of the organizations in which we work, even when that hierarchy has failed to respond. This is an aspect that strains mental health nursing and maintains the acceptance of practices that may be ethically distressing to staff and non-therapeutic to patients.

For full transparency, where I rely on information gained from my own clinical practice, I have done so in a manner that would not reveal the identities of patients or colleagues. Personal medical information and identifying details are omitted as per Ontario's *Personal Health Information Protection Act* (2004). What I have done is grafted stories together to foreground the practice issues and critical themes.

This paper is not a critique of the dedicated staff that work in inpatient psychiatry. It is an acknowledgement of the constraints we work under. It is also an expression of interest to openly problematize those constraints outside the immediate pressures of daily work; including and especially the pressure felt when an involuntary patient persistently knocks on the nursing station window requesting to go out. This paper asks if everyone might deserve a little more breathing room.

I. CANADIAN LEGAL SYSTEM

To situate the MHA in the context of human rights law requires an overview of legal jurisdictions. In Canada, legislative responsibilities of the law were divided between the provincial and territorial, and federal governments with the *Constitution Act* (1867) (hereafter the Constitution). Each Province is responsible for the administration of both hospitals and civil and criminal justice related to provincially administrated powers (Constitution Act, 1867, s. 92(6, 7, 14)). Human rights in Canada were added to the Constitution in 1982 with the addition of the *Canadian Charter of Rights and Freedoms* (hereafter the Charter) (s 15, Part I of the Constitution Act; Foot, 2013). The very first section of the Charter establishes that all rights are subject to limits:

> The *Canadian Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.

All Canadian provinces operate under the common law tradition with the exception of Quebec (which operates under the civil law tradition) (Department of Justice of Canada, 2016). Common law, described by the Department of Justice of Canada, is "a system of rules based on precedent" (About Canada's System of Justice, 2017: np). When there is a conflict or question around an ambiguity of the law, a case can be brought to the courts. A judge's decision will, subject to the rules of constitutional law (including that applicable to statutory interpretation), interpret the ambiguity of the law in question in keeping with the ways judges interpreted the same laws in previous cases. The rulings made by each judge sets new precedents for how those laws should be interpreted in future. This is the system of case law.

The day I met Justice Leonard at his wood-paneled chambers, he excused himself for requiring a few minutes before we stepped out to lunch. From behind his desk piled with papers, he scrolled through emails. "The rulings from the court of appeals are released at noon," he explained as he scanned through a list. "Sometimes," he said, "there will be a ruling related to the case you're hearing that very day." This is how dynamic laws are in the nucleus of their operations; daily the judge must check what laws have changed because they may affect rulings made for cases they hear in the afternoon.

Apart from the courts, federal and provincial legislatures can amend existing laws and write new laws. That new legislation then "takes the place of common law or precedents dealing with the same subject" (About Canada's System of Justice, 2017: np). Provincial governments are responsible for legislation relating to hospitals, including civil commitment. Conflicts related to provincial legislation, such as whether patients confined under civil commitment should be entitled to outdoor access, can be resolved in a superior court of the province or escalated to the Supreme Court of Canada.

II. INTERNATIONAL HUMAN RIGHTS LAW

Human rights are specifically defined as "the set of entitlements held to belong to every person as a condition of being human" (OED, 2009). When in 1948 the United Nations General Assembly passed the *Universal Declaration of Human Rights* (1948) (UDHR), the principle of universality became the crux of international human rights law (UN Human Rights Office of the High Commissioner, nd). This means that human rights are understood to be applicable to all people. The United Nations and other international bodies have created numerous documents that continue to define and refine human rights for specific populations, like prisoners, people with disabilities, or people with mental disorders. These are international human rights instruments, legal tools that may be used to interpret laws.

International instruments can be binding or non-binding (Arena Ventura, 2014). A non-binding document presents ideals that courts can use as examples for what a group of international legal experts agreed upon for a particular issue. A binding document is one that has been ratified or signed by a nation to endorse the contents of the document,

but neither a binding or non-binding law necessarily have attendant enforcement mechanisms until they are formally incorporated into domestic legislation. The absence of an enforcement mechanism is a vital point here. Lawyer Martin emphasized:

> Unless we have an enforcement mechanism by which people who are aggrieved by violations of those rights can have those rights addressed, like a court or a tribunal, it can be very difficult to enforce a right. The practical aspect is: how accessible is the enforcement mechanism? Do you have to run a court case to get it? In that case, it is inaccessible to a lot of people. Or is there a tribunal or a commission, like the provincial human rights commissions, that have some procedures in place to make it more accessible?

Legislation like the MHA should be interpreted so as to comply with human rights law (provincial and federal) and federal human rights law should be interpreted so as to comply with international human rights law. It is all well and good to refer to the 'rights' in these international instruments: but they need enforcement mechanisms, as lawyer Martin emphasized.

III. KEY ISSUES OF CIVIL COMMITMENT AND OUTDOOR ACCESS IN ONTARIO

1. Outdoor Access and Coercion

Under section 27(1) of the MHA, patients may be granted a leave of absence or "passes" off the unit by their physician. Pass policies are developed at the level of each individual hospital or institution and passes are negotiated between a patient and their psychiatrist. Importantly, passes are not universally implied for those admitted under voluntary status – voluntary patients must also negotiate passes with their doctor. If a team or doctor does not trust that a voluntary patient will return to a unit safely, the choice is: discharge yourself against medical advice or stay inside. This is, of course, not a choice in the true spirit of the word.

Pass policies are a source of great tension in the nurse-patient relationship, which is the very core of nursing and is the nurse's greatest, most powerful tool, especially in mental health (CNO, 2013: 3). Staff frequently debate pass policies, but Rose explained, "everyone understands the reasoning for it, from a safety perspective." She elaborated:

> There were sentinel incidents where patients had gone out on pass and committed suicide. And the hospital felt like they had to react. The pass policy became more strict. … It makes sense, but it doesn't make sense, if that makes sense. Sometimes we have involuntary patients who are there for years. Can you imagine not seeing outdoors for an entire year? Knowing that that's what people need to be mentally healthy, it's tough.

Safety is typically signaled by cues of cooperation from patients. Risk is generally assumed and assessed to be reduced based on measures such as medication compliance and patient participation in treatment; according to GD Glancy & G Chaimowitz (2005), these follow evidence-based practice principles (15). But, this can amount to well-intentioned coercion. For example, in settings that do not have courtyards, like most acute units, passes to the courtyard can be used as an incentive for patients to agree to take medications. Rose acknowledges that access to the outdoors is used as leverage in bargaining tactics with patients. "For example, it's: if you take your medication, you can have a pass." This is a practical example of the 'threat' implied in the most accepted definition of coercion articulated by Alan Wertheime as a conditional proposal where if the proposal is rejected, the person will be left "worse off according to a 'moral

baseline,'" which is defined as a liberty "one is normally entitled not to be deprived of" (Szmukler, 2015: 1).

I asked Rose how she feels about this:

> I do think you have to be creative in ways to treat people, unfortunately. And that might be a creative way to do so, even though it's coercive. But psychiatry struggles with coercion on a daily basis. Especially because it's [access to the outdoors] something that should just be a given right.

Indeed, informed consent as an aspect of ethical health care is challenged when a patient is not considered "safe" to access the outdoors without agreeing to take medication. Legal scholars have questioned whether free and informed consent is even possible under involuntary hospitalization where conditions enable 'soft coercion' (Gupta, 2003: 172).

I asked Rose how patients feel about the pass policy from her perspective. She answered:

> "A lot of remarks are that it's a human rights violation. You hear that a lot."

2. Prolonged Confinement

Though the MHA does not protect a person's ability to access the outdoors, it does make provisions for an accessible enforcement mechanism for inpatients to challenge involuntary hospitalization or incapacity via the Consent and Capacity Board (CCB). The CCB is an independent body created by the provincial government of Ontario to review MHA certificates. Every certified patient is entitled to a review if they so choose.

Under the MHA, a person hospitalized involuntarily or found incapable of making treatment decisions is automatically seen by a Rights Adviser (MHA, Rights adviser, s. 38(3)). The Rights Advisor explains the meaning of the certificates their psychiatrist has enacted and informs the patient that they may challenge the assessment at a hearing with the CCB (MHA, Rights adviser, s. 38(3)). If the CCB sides with the psychiatrist for either involuntary admission or a finding of incapacity, the patient does have one further mode of recourse. The CCB decision can be appealed to the Ontario Superior Court of Justice (MHA, Appeal to court, s. 48(1)). Though this is intended to honour the patient's autonomy and choice, an appeal to the Superior Court can result in a shockingly long hospitalization for a patient awaiting a court date. Between 2003-2004, the average wait for the court to return a decision from the time the appeal was filed was 8 months (Zuckerberg, 2007: 526). I mentioned this statistic to Rose who replied: "I think it's longer." The Ontario Superior Court could not offer more recent statistics than those quoted by Zuckerberg as of 2018. Indeed, we had both worked with clients who waited over a year for their day in court.

I asked each of the lawyers interviewed if they thought it was reasonable to keep a person in this particular quagmire confined to a mental health unit without access to the outdoors. Justice Leonard answered simply: "No." John sharply hammered the point: "Even Paul Bernardo [an infamous rapist and murderer] gets an hour a day outdoors. On his own. But he gets it."

Patients with dementia compounded by a mental health history are another population that endure long hospitalizations. Lack of supportive housing is widely recognized as a major bottleneck in the mental health care system. The 2016 Annual Report of the Office of the Auditor General of Ontario stated:

> We found that in the last five years approximately one in ten beds in specialty psychiatric hospitals was occupied by someone who did not actually need hospital care but could not be discharged due to the lack of available beds in supportive housing or at long-term care homes. Over the past five years this problem has become worse (Ministry of Health and Long-Term Care, 2016: 619).

General hospitals face the same barriers. Social workers require Herculean tenacity to find long-term care for clients with dementia and a mental health history, especially if that person has been violent. In my experience, these people are often held involuntarily in acute units because of the high level of care they require. They do not go outside until they leave feet first, to put it crudely.

In 2014, a man who had been detained at a psychiatric hospital for nineteen years brought a case to the Ontario Court of Appeals on the grounds that his Charter rights had been violated in his detention (Grant & Carver, 2016). The judge in *PS v Ontario* (2014) determined indefinite detention without review was unconstitutional in civil commitment. As such, Ontario's MHA was in contravention of section 7 of the Charter because "it provided for long-term commitment [detention of six months or longer] without adequate procedures to protect the liberty interests of the person committed" and "fail[ed] to give the CCB the necessary tools to protect the liberty interests of long-term detainees" (Grant & Carver, 2016: 1003, 1009). Bill 122*, Mental Health Statute Law Amendment Act* (2015), the result of *PS v Ontario*, empowers the CCB to order facility transfers; leaves of absence; change of security level or privileges; supervised or unsupervised access to the community; or vocational, interpretation or rehabilitative services (List of Board orders s. 2(1-5)). Prior to Bill 122, the CCB had no jurisdiction over the conditions of confinement. This is a very positive change.

Legal scholars Isabel Grant & Peter J. Carver (2016) highlight that this ruling has identified a shortcoming in mental health laws across Canada. With the exception of Ontario:

> no provincial mental health legislation in Canada provides the kind of jurisdiction envisaged by the Ontario Court of Appeal in PS to supervise the conditions of long-term commitment (Grant & Carver, 2016: 1013).

PS v Ontario gives lawyers and citizens a tool to challenge the lack of power other provincial tribunals have to make a meaningful impact on the treatment and conditions of care of detainees (Grant & Carver, 2016: 1014). Grant & Carver also acknowledge that:

> The decision, and Ontario's legislative response also leave open the pressing question of the scope of liberty interests guaranteed by section 7 for those who are civilly committed for shorter periods of time (999).

According to the Canadian Institute for Health Information (2018) the average stay for an inpatient on a mental health unit is 70 days, and many people who have had an inpatient psychiatric admission in Canada tend to cycle in and out of hospital. Between 2003 and 2004—the most recent data tracking patients for more than a month after

their discharges from hospital—37 percent of people treated for a mental disorder across the country were readmitted within one year (Madi, Zhao & Fang Li, 2007). Ninety-eight percent of people who are civilly committed are hospitalized for less than six months, meaning these new powers invested in the CCB affect only 2% of involuntarily hospitalized people (Grant & Carver, 2016: 1008). Only the 2% can seek an order affecting what is categorized as the privilege of having access to even a restricted part of the outdoors

The CCB is currently invested with the power to order outdoor access for long-term detainees, and so it should. However, without legislation requiring hospitals to have secure outdoor space, it could prove difficult to materialize this power. Further, the power to address such conditions of care should not be restricted to long-term detainees. Whether confined for six months, six weeks, six days or six minutes, liberties should be protected.

3. Long-Term Care

Confinement without outdoor access is also not exclusively restricted to mental health units; there are other hospital areas and institutions that are designated to have secure units where the exit doors are locked. Units in long-term care facilities where people with dementia live out their days are locked for safety. Recent reforms to Ontario's *Long-Term Care Homes Act* (2007) (LTCHA) include processes that mirror those of the MHA relating to confinement, and that carry the spirit of use of the least restrictive means required to mitigate risk posed by a person. Though not-yet-in-force at the date of publication and with no date yet named by the Lieutenant Governor for the commencement of these provisions, the reforms to the LTCHA will introduce providing the person with notice of confinement, contact with a rights adviser, and the ability to contest confinement via a CCB hearing (s.30(1-9) as amended by the *Strengthening Quality and Accountability for Patients Act* (2017). Since 2015, the *Long-Term Care Home Design Manual* dictates that:

> At least one outdoor space at grade level must be enclosed to prevent unauthorized entering or exiting from the home (Outdoor Space, 6.1).

This is an important measure towards better buildings, but this only applies to new constructions or renovations planned after February 2015. It does not require a retrofit to all long-term care homes. In the absence of legislation that requires outdoor access, it would not be a violation of rights to spend the rest of your entire lifetime indoors from the moment you are admitted to a dementia unit in a long-term care facility until the day you die. This is a future that current Ontario legislation makes possible.

4. Medical Considerations

Access to the outdoors is a component of both physical and mental health. Medical research on the importance of sunlight exposure for bone and dental health as a source of Vitamin D has led to the development of guidelines for the general public. The UK's National Institute for Health and Care Excellence (NICE) recommend at least 10 to 15 minutes of sun exposure without sunscreen to maintain adequate vitamin D supplies, for those confined indoors vitamin D supplements are recommended (NHS Choices, 2016). Sun exposure is also a vital element for good sleep hygiene. Exposure to sunlight

produces serotonin, a neurotransmitter that can effect positive mood and optimism; in darkness, serotonin is converted to melatonin, a neurotransmitter-like hormone that regulates sleep (Mead, 2008). A balance of serotonin can even effect positive mood and optimism (Mead, 2008). Because of the impact of sunlight on neurotransmitters and hormones that affect the circadian rhythm and mood, Russel J. Reiter, a professor in the department of cell systems and anatomy at the University of Texas Health Science Center, stresses that "it's important that people who work indoors get outside periodically" (Mead, 2008: np). Sleep hygiene is vital to good mental health for all and mental health settings should be designed to facilitate behaviours that support good mental health.

5. The Built Environment and Health Outcomes

The connection between mental health and the built environment has been widely researched. However:

> the weight of the evidence is relatively weak, relying principally on small convenience samples and cross-sectional study designs or short-term follow-up (Rugel, 2015: 1).

Despite multiple studies linking green space to improved mental health:

> in medical fields, a randomized controlled trial or experiment is considered the strongest research design for generating sound and credible empirical evidence (Ulrich, Zimring, Zhu, DuBose, Seo, Choi, Quan, & Joseph, 2008: 103).

Roger S. Ulrich, a professor of architecture, has researched the effects of nature on health in a manner consistent with the evidentiary regime of the randomized control trial.

In 1984, Ulrich wondered if a view to the outdoors would be therapeutic to patients and, accordingly, their recovery. Aided by the layout of a post-surgical unit in a suburban Pennsylvania hospital where patient rooms faced either a "small stand of deciduous trees or a brown brick wall," Ulrich was able to randomize participants to study the effect of nature on patients recovering from cholecystectomy (gallbladder removal) (Ulrich, 1984). His findings showed:

> the patients with the tree view had shorter postoperative hospital stays, had fewer negative evaluative comments from nurses, took fewer moderate and strong analgesic doses, and had slightly lower scores for minor postsurgical complications (Ulrich, 1984: 421).

Ulrich notes there is a constant pressure in health care to reduce costs and yet improve quality of care. To persuade hospital administrators and decision-makers to allocate resources to a courtyard garden, for instance, there are three kinds of convincing evidence: health outcomes, like decreased blood pressure readings; economic measures, like cost-saving on medications; or patient reported satisfaction. His 1984 study provided firm ground to defend the role of nature in healing and showed that sometimes clinical indications overlap with economic outcomes; for example, how decreased use of medications like analgesics or anxiolytics, or decreased length of stay can lower costs in patient care (Ulrich, 2002).

A literature search turned up numerous articles on outdoor exposure as a benefit to certain mental health disorders – anxiety and depression – but rarely were psychotic

disorders examined, even though this subpopulation are more likely to require inpatient hospitalization. (See, for example, Emily Rugel's (2015) excellent survey of research examining the impact of nature on health, *Green Space and Mental Health: Pathways, Impacts, and Gaps*.) More attention in health research in terms of non-medical interventions like outdoor access, exercise, and occupational engagement for psychotic disorders like schizophrenia is desperately needed.

IV. OUTDOOR ACCESS IN CIVIL COMMITMENT VS. HUMAN RIGHTS LAW

In Canada, if a lawyer were to make a legal claim for health and wellness, such as oa person needs sun exposure for bone health, the Charter would be the most useful piece of legislation to ground the claim. Martin is familiar with using the Charter in this way. He pointed me to section 7 of the Charter (life, liberty and security of the person), which he and his colleagues have used to build cases in the past.

> We have tried to link the idea that your health is an expression of security of the person. So, you can have threats to your life or threats to the security of the person through things that are damaging to your health. Environmental harms are harms to health, usually, but the case law in this area is limited and usually the threat to health has to be severe.

Martin added the sobering reminder: "There's no free standing constitutional right to be healthy."

To my knowledge, there have been no civil suits about outdoor access while under civil confinement in Ontario, but there have been cases that challenged civil commitment. Lawyer and legal scholar Joaquin Zuckerberg (2007) found in his review of case law pertaining to involuntary hospitalization without treatment that the practice is not inconsistent with interpretations of section 7 of the Charter, because:

> the legislation is designed to protect persons who pose a danger to themselves or to others (516).

Without a legal precedent to help explain outdoor access as a human right, I compared the MHA to international instruments that might give guidance, such as the UDHR, and the *UN Principles of the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care* (1991) (MI Principles), and to policies in other secure settings such as prisons for criminal commitment and detention centres for those found to be in violation of immigration law. Who gets to go outside?

Below is a list of international instruments and local legislation to show how local Ontario law fits within the federal and international legal contexts.

International Human Rights Instruments	
Binding	**Non-Binding**
International Covenant on Civil and Political Rights (1966)	UN Declaration of Human Rights (1948)
International Covenant on Economic, Social and Cultural Rights (1966)	UN Principles of the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (1991)
Convention on the Rights of Persons with Disabilities (2006)	UN Standard Rules for Equalization of Opportunities for Persons with Disabilities

	(1993)	
	General Comments 5 (1996) and 14 (2000) of the International Covenant on Economic Social and Cultural Rights	
	WHO's Mental Health Care Law; ten basic principles (1996)	
	WHO Guidelines for the Promotion of Human Rights of Persons with Mental Disorders (1996)	
Domestic Human Rights Instruments		
Constitutional	**Provincial**	**Related Commission**
Charter of Rights and Freedoms (1982)	Ontario Human Rights Code (1962)	Human Rights Tribunal of Ontario (HRTO)
Provincial Legislation Related to Involuntarily Hospitalized Persons		
	Related Commission	
Mental Health Act, RSO, 1990	Consent and Capacity Board	
Health Care Consent Act, S.O. c.2 Sched. A (1996).		
Personal Health Information Protection Act, 2004, S.O. 2004, c. 3, Sched. A	Information and Privacy Commissioner	

1. Freedom of Movement

The UDHR states:

> Article 13 1.
>
> Everyone has the right to freedom of movement and residence within the borders of each State.

Consistent with the above law, the Charter does include freedom of movement as a right; however, section 7 addresses deprivation of liberty.

> Section 7.
>
> Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

And section 9 states:

> Section 9.
>
> Everyone has the right not to be arbitrarily detained or imprisoned.

These rights are subject to limits by section 1 of the Charter, which further necessitates the "least restrictive" principle of the MHA, which is obliged to be consistent with the Charter. The MHA does address this in section 41.1:

> *Factors to consider*
>
> (3) 6. Any limitations on the patient's liberty should be the *least restrictive limitations* that are commensurate with the circumstances requiring the patient's involuntary detention. 2015, c. 36, s. 10. (*italics mine*)

This consideration aligns with the MI Principles' Principle 9, which states:

> *Treatment*
>
> Every patient shall have the right to be treated in the least restrictive environment and with the least restrictive or intrusive treatment appropriate to the patient's health needs and the need to protect the physical safety of others.

The MI Principles also include some detail on what the conditions of a treatment facility should be.

> Principle 13
>
> *Rights and conditions in mental health facilities*
>
> 2. The environment and living conditions in mental health facilities shall be *as close as possible to those of the normal life* of persons of similar age and in particular shall include:
>
> (a) Facilities for recreational and leisure activities … (*italics mine*)

There are no explicit inconsistencies between the MHA and these international instruments. Access to the outdoors is not explicit. However, might it be assumed that most people go outside regularly during their "normal life?" It did appear as though an argument could be made. I asked John if section 7 of the Charter might encompass freedom of movement. He replied, "I think it could. I think there's an argument to be made there." There appears to be reason to argue that outdoor access is implied as a human right in the Charter. I wondered if a civil suit brought before the courts about a person's right to outdoor time in hospital had any potential to change the legislation. John answered: "Oh I think that could happen. That's theoretically possible." Then, considering his work with the Ontario Review Board, (a tribunal that deals with people deemed Not Criminally Responsible by reason of mental disorder or unfit to stand trial), he added:

> But find me a lawyer who's going to take the time and energy required to bring that kind of suit on behalf of someone who's been charged criminally and detained. I mean, you could see it if someone were absolutely innocent, wrongfully imprisoned, and had deep pockets, and maybe, some sway in the community. But where's the money in that? Where's the benefit for the legal practitioners? And again, find me the political will to make conditions better for people who are accused of crimes. Or the mentally ill for that matter.

I asked: Might political will be lying nascent in Canada's aging population given that some will be affected by the lack of legislation for outdoor access especially in long-term care facilities? "Of course," John said, "but who in their right mind is worrying what happens if I get dementia?"

2. Equality and Accessibility

Another line of argument for outdoor access for patients in hospital could be based on equality rights. Section 15.1 of the Charter, entitled "Equality before and under law and equal protection and benefit of law," states:

Equality Rights

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

Section 15.2, states:

Affirmative Action Programs

Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

Section 15 of The Charter addresses accessibility for people with disabilities. Further, Rule 5.a in the non-binding *UN Standard Rules for Equalization of Opportunities for Persons with Disabilities* (1993) articulates the responsibility of states to create accessible buildings for those with disabilities:

Access to the Physical Environment

1. States should initiate measures to remove the obstacles to participation in the physical environment. Such measures should be to develop standards and guidelines and to consider enacting legislation to ensure accessibility to various areas in society, such as housing, buildings, public transport services and other means of transportation, streets and other outdoor environments

and

3. Accessibility requirements should be included in the design and construction of the physical environment from the beginning of the designing process.

It could be argued that a hospital providing mental health services ought to ensure outdoor space is accessible to involuntary patients on the basis that a mental disorder requiring involuntary hospitalization is considered a disability. Further, legislation ought to support this. Just as for other disabilities, consideration of access to the outdoors in the case of involuntary hospitalized patients should be part of the accessibility considerations of a hospital architect.

V. CANADIAN PRISONS AND DETENTION CENTRES

To follow the patient's assertion that he would be granted an hour of fresh air in prison, I reviewed the federal *Criminal Code* (1985). I found no mention of access to the outdoors for prisoners in this legislation. However, in May 2018, the *Correctional Services Transformation Act* was passed by the Ontario government. Included in this legislation is the introduction of Schedule 2: *Correctional Services and Reintegration Act* (2018) that defines conditions of custody for Ontario prisons, including outdoor access. It states:

Recreation

61 (1) Every inmate shall be offered the opportunity to participate in a minimum of one hour of recreation time each day.

Indoors or outdoors

(2) The inmate shall be allowed to choose whether to spend the recreation time indoors or outdoors.

Prior to this Act, Ontario law made no mention of outdoor access for inmates of provincial prisons. Documents provided by Correctional Service of Canada (CSC)[1] explained that daily fresh air is intended to be offered inmates in provincial and federal prisons. But both the *Inmate Information Guide for Adult Institutions* (2015) for provincial prisoners and the Commissioner's Directive 566-3 (2012): *Inmate Movement* for federal prisoners failed to indicate of the duration or frequency of access to the outdoors. These two documents, referred to outdoor access as the "Fresh Air Program." The *Correctional Services Transformation Act* (2018) provision for outdoor access for prisoners stands in contrast to the MHA which makes no such provision.

I asked interviewees if the MHA should likewise address conditions. John said:

> I think it should. Yes, I do. I think there should be a … basic minimum standard by which all institutions are held. Absolutely.

With regards to how much time should be given outdoors each day, Leonard said:

> In my view, I think everyone ought to be entitled to at least an hour a day.

Across Canada, each province has its own legislation governing provincial prisons. Of the ten provinces in the country, four have encoded outdoor access for prisoners in their law - Nova Scotia, Ontario, Alberta and British Columbia.

Province	**Law**	**Provision for Outdoor Access**
Nova Scotia	Correctional Services Act (2005)	57 (1) A superintendent shall ensure that every offender is allowed at least thirty minutes a day for outdoor exercise.
Newfound-land	Correctional Services Act (2017)	None.
New Brunswick	Corrections Act (2011) (Updated March 29, 2019).	None.
Prince Edward Island	Correctional Services Act (2017) Correctional Services Act Regulations (2004)	Neither of these documents address outdoor access.
Quebec	S-40.1 - Act respecting the Québec correctional system (Updated 10 December 2019)	None.
Ontario	Correctional Services and Reintegration Act (2018)	*Recreation* 61 (1) Every inmate shall be offered the opportunity to participate in a minimum of one hour of recreation time each day. *Indoors or outdoors* (2) The inmate shall be allowed to choose whether to spend the recreation time indoors or outdoors.
Manitoba	The Correctional Services Act (1998) (Updated January 31,	None.

[*] Dr Sarah Amy Jones, Consultant Old Age Psychiatrist, Rotherham, Doncaster and South Humber NHS Foundation Trust; Dr Bushra Azam, Consultant Old Age Psychiatrist, Derbyshire Healthcare NHS Foundation Trust, Dr Kevin Morgan, Consultant Old Age Psychiatrist, Rotherham, Doncaster and South Humber NHS Foundation Trust; Dr Navjot Ahluwalia, Consultant Psychiatrist, Executive Medical Director, Rotherham, Doncaster and South Humber NHS Foundation Trust.

	2020).	
Saskatch-ewan	The Correctional Services Act (2012) as amended by The Statutes of Saskatchewan, 2013, c.27; 2014, c.E-13.1; 2016, c.28; 2017, c.P-30.3; and 2019, c.Y-3, c.18 and c.25.	None.
Alberta	Corrections Act (2000) (Updated 11 December 2018) Correctional Institution Regulation (2001)	No provision for outdoor access. Part 2: Inmates Exercise of inmate 26 An inmate is entitled to exercise daily in the open air, weather permitting, when staff, space and facilities are available.
British Columbia	Correction Act (2004) (Updated 22 January 2020.) Correction Act Regulation (2005)	No provision for outdoor access. *Inmate privileges* 2 (1) (b) a daily exercise period of at least one hour, in the open air if weather and security considerations allow

VI. ONE HOUR OF FRESH AIR A DAY – ORIGINS IN THE LAW

I asked each of the legal professionals I interviewed what they might recommend reading on the topic of "one hour of fresh air a day" for confined persons in the law. John suggested I look to the Geneva Convention for Prisoners of War. He advised:

> That is instructive because you're talking about wartime. It doesn't get more intense than war time.

Chapter V of *The Geneva Convention Relative to the Treatment of Prisoners of War* (1929) (ratified by Canada in 1933) does encode a standard for outdoor access (International Committee of the Red Cross).

> *Religious, Intellectual and Physical Activities*
>
> Article 31
>
> Prisoners shall have opportunities for taking physical exercise, including sports and games, and for being out of doors. Sufficient open spaces shall be provided for this purpose in all camps.

Further, the *Mandela Rules* adopted by the UN in 2015 defines a minimum standard for the amount of time a person ought to be permitted out of doors while a prisoner.

> *Exercise and sport*
>
> Rule 23 1.
>
> Every prisoner who is not employed in outdoor work shall have at least one hour of suitable exercise in the open air daily if the weather permits

In Canadian detention centres, the Canadian Border Services Agency states that:

> A minimum of one hour of suitable exercise in the open air on a daily basis, weather permitting, shall be made available to all detainees at facilities with a capacity of more than 24 detainees (Personal Correspondence, October 21, 2016.)

Though all human beings are entitled to all human rights, those detained by Border Services and Corrections in Canada are, upon paper, promised an hour of fresh air a day while those confined under the MHA are not. Whether daily access to fresh air is provided in practice is another question.

VII. LEGAL CHANGE FOR OUTDOOR ACCESS FOR MENTAL HEALTH SETTINGS IN THE USA

Access to the outdoors and fresh air programs of inpatient mental health services recently became part of state legislation in Massachusetts, in large part due to the committed work of Jonathan Dosick, a mental health advocate and service-user who began to investigate outdoor access in psychiatric settings in 2003 as a part-time employee with Massachusetts' Disability Law Centre (Mental Health Legal Advisors Committee, 2015). An article in *STAT* quoted Dosick's stand on fresh air as a fundamental right. He said:

> Prison inmates are allowed outside by law... Even organic livestock, they have laws protecting them. What does that say about people with psychiatric conditions?. (Bailey, 2016: np).

After a decade of dogged advocacy for the addition of outdoor access to the state of Massachusetts's Five Fundamental Rights for patients that protect access to telephones, mail, visitors, privacy and dignity, and legal council, Governor Deval Patrick signed off on the Fresh Air Bill which took effect April 6th, 2015 (Mental Health Legal Advisors Committee, 2015). There were not, however, any concrete guidelines for implementation and in July of 2016, approximately one-third of the state's hospitals were in search of waivers to the new rules "citing lack of space," or "concerns about safety, staffing, space and liability" (Bailey, 2016: np). It is still yet to be seen how the Bill will transform psychiatric services in Massachusetts, but "to those who have ever experienced life inside a psychiatric hospital or other inpatient facility, the promise of even temporary reprieve from the confines can have important implications for those persons' mental health and recovery prospects" (Mental Health Legal Advisors Committee, 2015).

VIII. SUMMARY

Ontario's mental health legislation is not unique for neglecting to include outdoor access. As mental health programs create their own hospital pass policies and the Ministry of Health and Long-Term Care does not require that those institutions be designed with secure outdoor space, there is no guarantee of access to the outdoors under civil commitment. While confinement is common to involuntary hospitalization and prisons, the carceral spaces in Ontario now protect a person's access to the outdoors while hospitals do not. Patients held under civil commitment for mental health treatment should, theoretically, be able to maintain their civil rights except for their right to leave the hospital. The 13th MI Principle of "the least restrictive environment" states conditions

of mental health care should be "as close as possible to those of the normal life" (MI Principles, 1991, 13.2.a). Access to the outdoors in civil commitment is a question of human dignity and civil rights. *PS v Ontario* has laid fertile ground to for those hospitalized involuntarily to question what liberties section 7 of the Charter ought to guarantee (Grant & Carver, 2016: 999). Patients on mental health units in general hospitals do not get to exercise freedoms patients on other hospital units can. Patients on other units can go outside for fresh air and a change of pace; but it is accepted that outdoor access cannot be offered to involuntary mental health patients due to architectural constraints. Confinement has been viewed by the medical community as an inconvenience of treatment rather than as a deprivation of freedom. From a disability rights perspective, as mental health disorders fit under the umbrella of disability, access to the outdoors for involuntary patients should be part of the accessibility considerations of a hospital board of directors and the architect they select to design a mental health unit.

Cor Wagenaar wrote in his introduction to *The Architecture of Hospitals* (2006) that hospitals:

> [R]eveal how society treats its citizens once they have fallen victim to illness and injury. They represent social and cultural values, and since the late eighteenth century, they have manifested the way science and philosophy conceives the origins, causes and cures of diseases (11).

What is revealed in both mental health legislation and health care practices is that our society believes that it is reasonable to restrict the freedoms of people with mental health disorders in ways we do not believe prisoners or prisoners of war should have their freedoms restricted. This may also reflect a modern neglect of the relationship between humans and nature as a component of health and a hierarchy for where attention is placed in health research. As Ulrich (2002) reminds us, without evidence upon which to base a change in health care practice, change is nearly impossible. As basic as a breath of fresh air may be to good mental health and communicating care for a whole person, the basis upon which to rest this claim is currently thin.

IX. CONCLUSION

We cannot compartmentalize how we think of mental health, physical health and safety, medicine and the law to such a point that we permit such blind spots in legislation and practice. The denial of outdoor access to involuntary mental health patients should receive attention from hospital decision-makers and ministry policy makers. Perhaps professional legislation must change. Perhaps the College of Nurses of Ontario's policy on restraints must change to include a subsection that says:

> You cannot deny your patients a right that through international law our government has agreed should be given to prisoners of war.

Perhaps the laws must change.

I have seen ways mental health professionals have conspired in hope to improve the quality of outdoor access for their patients. One unit fundraised for months among hospital staff to purchase greenery for their courtyard. These are great things, but they do not address the systemic problem – that our government does not protect a human's right to access the outdoors. While John warned of the unlikelihood that a lawyer would

take interest in building a case to change this, I am, as a nurse, aware of a further barrier: patients that are most acutely affected by limitations to outdoor access are often those least equipped to organize something like a legal challenge. Individuals with severe persistent mental illness or people with dementia awaiting a bed in long-term care are populations that endure the lengthiest admissions to hospitals. Beyond finding creative ways of convincing patients to comply with care plans so they may gain passes, there is little a nurse can do to prioritize their will to go outside. That will exists. Sometimes, that will is ferocious and expressed with fists pounding upon a plexiglas partition between the nurses and the patients. Sometimes that will is defeated after prolonged months of receiving the same answer: "I can't let you outside." Which of the two responses is most distressing to me as a nurse and as a person is a toss-up.

It is encouraging that laws do and have and will change. Nonetheless, the lengths one must go to in order to pursue the chance to change a law is daunting. Ontario has benefitted from the efforts of PS and his lawyers willingness to lodge a court challenge, Massachusetts has benefitted from a sympathetic politician willing to write a law from the legislature. Hopefully, this paper might be useful to others who care to ask if everyone might deserve a little more breathing room.

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AN AUDIT OF DOCUMENTATION RELATING TO DECISION MAKING CAPACITY AT AN OLD AGE PSYCHIATRIC HOSPITAL IN ENGLAND

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ABSTRACT
The *Mental Capacity Act 2005* (MCA) guides clinicians in England and Wales in how to support patients to make a capacitous decision. Documentation of patients' capacity is mandatory for certain decisions in psychiatric hospitals so as to evidence the use of the MCA guidance. Given the importance of decisions such as where to live and what medication to take, the quality of clinician interview and documentation is important to monitor.
Method: The quality and quantity of decision-making capacity (DMC) documentation was reviewed in a psychiatric hospital in England for older adults. The clinical records of 49 discharged patients were examined retrospectively. All DMC documentation found was compared with existing legal guidance on capacity assessment.
Results: 46/58 DMC documents were found to be insufficient. There was little evidence of what information had been given to patients to enable autonomous decision making, what actions had been undertaken to optimise capacity and what alternative decision options were presented.
Conclusions: Consideration should be given by hospital managers to support DMC assessment by staff. Further reflection is needed on the part of regulators regarding the optimum DMC documentation standard, particularly regarding physical health medication for psychiatric inpatients. Guidance and training for all staff involved in the assessment and documentation of DMC should be made available.

I. INTRODUCTION

The statutory principles of the *Mental Capacity Act* (MCA) 2005 came into full force in October 2007 and applies to all persons over the age of 16 in England and Wales. The MCA is underpinned by 5 statutory principles:

(i) Capacity is assumed unless there is clear evidence it is lacking;
(ii) An unwise decision does not mean the individual lacks capacity;
(iii) If someone lacks capacity to make a decision, all practical steps must be taken to help the person make a decision;
(iv) Any decision made on someone's behalf because they lack capacity must be in their best interest;
(v) Any decision made on someone's behalf because they lack capacity should consider the least restrictive option).

A capacity assessment requires an assessment of whether there is a disturbance of mind or brain. If there is, then the assessor must assess the person further to

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determine whether the person can understand, retain, use and weigh the information and communicate their decision. This is referred to as the two-stage functional test.

Both the MCA Code of Practice (issued under the Act) and guidance from the General Medical Council specify that the process and outcome of capacity assessments should be documented in the patients' records(1–3). However, in 2014, a specially convened Parliamentary inquiry identified that capacity assessments were generally not recorded and were of poor quality (4).

Mental capacity law guidance (5) suggests that documentation is explicit regarding: what are felt to be the salient details the person needs to understand, the choices that are available and in evidencing each element of the capacity test. In addition, it must be made clear how the inability to make a decision is secondary to an impairment or disturbance of mind or brain (6).

Current guidance across England is for psychiatric inpatients to have documentation to evidence that their capacity has been assessed for the decisions to be admitted to hospital and to receive treatment. Recent case law has emphasised the importance of giving accurate information on the risks and benefits of a proposed treatment, alternative treatment options, tailoring the information to the patient and allowing time and space for the patient to consider the information (7).

Despite the MCA being in force for some years, there are concerns that there are challenges facing clinicians when translating knowledge into practice (8) With this in mind, this study aimed to assess the quality of decision-making capacity (DMC) documentation at an old age psychiatric hospital in England. The implications for practice and challenges of addressing them will be discussed.

II. METHOD

A retrospective audit of the clinical records of all patients discharged from two wards at The Woodlands Unit, Rotherham, England between January and November 2016 was undertaken.

Both wards provided care for patients aged over 65. One ward specialised in the care of patients with dementia, whilst the other ward specialised in treating patients with mood disorders and psychosis.

The paper and electronic records of 49 patients were reviewed for evidence of documentation of DMC. Any documentation found was copied word for word and anonymised.

The decision being made and professional background of the person documenting the information was logged. This was carried out by authors 1 and 2 in January 2017.

All DMC documentation found was on a structured MCA1 Form: Record of Mental Capacity Assessment(9). For the purposes of analysis, this form was divided into 7 sections: the decision to be made; the disorder of mind/brain; the ability to understand, retain and weigh up the relevant information; the communication of the

decision, and the assessment outcome (Table 1).

AUDIT STANDARDS

Each section of documentation was independently rated as sufficient or insufficient by authors 1 and 2 based on the audit standards detailed in Table 1. The standards were devised from current legal guidance (5).

If the MCA1 form had 4 or more sections rated as sufficient (i.e. meeting the audit standard), the overall form was given a sufficient rating. This cut off was chosen to reflect a hypothesis that most DMC documentation would fall below the standard described in the legal guidance. Any discrepancies were discussed between the two authors until consensus was reached.

Table 1 – Audit standards used by the authors to rate DMC documentation found as sufficient or insufficient

Section of MCA1 form	Audit standard to be met in order for the section to be marked as sufficient
1. The decision capacity is being assessed for	Must be a single decision
2. Is there an impairment of or disturbance in the functioning of the person's mind or brain?	Must state more than a diagnosis alone and describe aspects of behaviour or functioning that may have an impact on decision making
3. Is the person able to understand information relevant to the decision?	Must state what are felt to be the salient details the person needs to understand Must state what was done to assist the patient in understanding information
4. Is the person able to retain the relevant information?	Must state what was done to assist the patient in retaining information e.g. offering written information
5. Is the person able to use or weigh the information as part of the decision making process?	Must state which available choices were discussed
6. Is the person able to communicate their decision?	Must state how the patient communicated their decision
7. Outcome with rationale	If the outcome is that the patient lacks capacity, the assessor must refer to which elements of the capacity test (i.e. sections 3-6 of the form) the patient failed on

This project was reviewed by the NHS Trust audit department. No ethical approval was required for the study as it was an investigation of clinical data already required as part of routine care. The only personal identification collected for each patient was an NHS number. All data was stored anonymously in a password protected file on an encrypted computer.

III. RESULTS

There were 58 assessments of DMC documented relating to 27 patients. 22 patients had no assessments of DMC for any decision documented. 12 of the 58 DMC documents were rated as sufficient overall when judged against the criteria described in Table 1.

AUDIT STANDARDS

Table 2 shows the results relating to each standard. The most common decisions for which DMC documentation was completed were whether to accept treatment, followed by a combined decision for admission and treatment (Table 3). Where MCA assessment documentation was for a dual decision (admission and treatment), this automatically led to a rating of insufficient for the "decision" section as the MCA is clear that each assessment should be for a single decision only.

Documentation on sections 2-5 of the forms was frequently judged insufficient due to the professional completing it re-stating the question rather than giving evidence specific to the patient; failing to mention what information was provided to the patient, including what options were discussed; failing to describe what was done to assist the patient in making the decision; and not describing the patient's impairment or disability that impacted on their ability to make a decision (Table 2).

Table 2 –The proportion of each section of the MCA1 forms rated sufficient and insufficient with examples.

Section of MCA1 form	**Number of Forms rated insufficient (not meeting The standard)**	**Number of Forms rated sufficient (meeting the standard)**	**Example quotes from documentation judged to be insufficient**	**Example quotes from documentation judged to be sufficient**
1. The decision capacity is being assessed for	19	39	Admission and treatment	Informal admission to a mental health unit
2. Is there an impairment of or disturbance in the functioning of the person's mind or brain?	10	48	X has got a diagnosis of Lewy body dementia	Attempted suicide by cutting his wrists/ paracetamol overdose
3. Is the person able to understand information relevant to the decision?	38	20	X cannot understand instruction due to Alzheimer's disease	X was able to partake in the assessment. Her thought process was logical and rationale there was no evidence of confusion
4. Is the person able to retain the relevant information?	45	13	Unable to retain adequately to weigh up information	X was able to comprehend the information and was aware that the unit was a mental health
5. Is the person able to use or weigh the information as part of the decision making process?	45	13	She cannot understand the necessity in the first place Lack of insight limits this	X was happy for support/help. He told me he was unable to keep himself safe at home alone and insightful that he requires help/support.
6. Is the person able to communicate their decision?	30	28	X has expressive dysphasia Does not communicate	No issues identified during the assessment, able to communicate verbally, speech coherent

7. Outcome with rationale	34	24	Yes as above X lacks capacity to give her consent to stay on the ward informally	X lacks capacity as she cannot understand, retain, weigh up information or communicate a decision

Table 3 – Decision to be made and the judged overall adequacy of DMC documentation.

Decision	**Total number of documents**	**Sufficient evidence (more than or equal to four standards met on the MCA1 form)**	**Insufficient evidence (less than four standards met on the MCA1 form)**
Whether to accept treatment	23	5	18
Combined admission and treatment	19	3	16
Whether to be admitted	11	3	8
Whether to participate in completion of the Decision Support Tool*	2	0	2
Whether to contribute to a decision regarding nursing interventions	2	1	1
Whether to appeal against detention in hospital under the Mental Health Act	1	0	1
Total	58	12	46

* The Decision Support Tool is a document designed to be completed a by a multidisciplinary team about a patient to identify whether their care needs meet the threshold for continuing healthcare funding.

PROFESSIONALS COMPLETING DMC

The majority of the DMC documentation was undertaken by doctors. Doctors' documentation of DMC was sufficient in only 6 out of 43 cases, whereas liaison nurses' documentation was found to be sufficient in all three cases (Table 4).

Table 4- Professionals documenting DMC assessments and judged adequacy of documentation.

Professional	**Total number**	**Number of Sufficient forms overall (i.e. with four or more sections marked as sufficient)**	**Number of Insufficient forms**
Consultant Psychiatrist	18	0	18
Specialty Doctor	17	5	12
Higher Psychiatry Trainee Doctor	1	0	1
Core Psychiatry Trainee Doctor	3	0	3
Foundation year 1 Doctor	4	1	3
Ward nurse	11	3	8
Liaison nurse	3	3	0
Unknown	1	0	1

IV. DISCUSSION

While several studies have previously examined the question of whether capacity is being assessed, there has been far less attention paid to the quality of capacity assessment. This study takes a step towards addressing this by focussing on the

documentation of mental capacity assessments. Documentation should be a reflection of what was discussed (10) and recording this accurately is important to protect both patients and doctors should a decision ever be challenged in the future. There have been criticisms of a doctor's record keeping in a high profile legal case relating to evidencing compliance with the MCA code of practice (11). With this in mind, documentation was classed as sufficient or insufficient based on legal guidance.

A previous audit of 68 entries relating to DMC found that in 58% of cases, the steps taken to assess capacity were described (12). In our audit, a lower proportion of documentation (12/58) was felt to sufficient. Although it is possible that detailed discussions are taking place but not being reflected in the documentation, the findings here are a cause for concern and undermine the progress that has been made in increasing the overall numbers of DMC assessments that are being conducted (13).

QUANTITY OF ASSESSMENTS

In England, the decision of whether to be admitted as a psychiatric inpatient must have associated DMC documentation. All psychiatric inpatients must also have DMC documented for treatment they receive. The Care Quality Commission monitor the standard of care provided in hospitals in England and routinely comment on MCA compliance in inspection reports(14).

22 out of the 49 patients' records reviewed for this study had no DMC documentation. This study, as have previous (17, 18) has demonstrated that there remains a significant number of patients admitted to old age psychiatric wards without documentation of their capacity to consent to admission or treatment. Previous studies have indicated that high levels of patients admitted to older adult psychiatric units lack capacity to make decisions regarding admission (48%) (17, 18) and treatment (62%) (16). Where patients are felt to lack capacity it is imperative that during DMC assessments clinicians are skilled at giving the patient the best chance to take part in decision making and can evidence this through documentation. The lack of descriptions in this sample of what was done to support patients to make capacitous decisions is concerning.

PARITY BETWEEN MENTAL AND PHYSICAL HEALTHCARE

A systematic review has found that there are similar proportions of patients who lack capacity to consent to admission and treatment on medical (34%) and psychiatric (45%) wards (17). In England, it is not mandatory for patients admitted to a medical hospital to have DMC documentation for the decisions to be admitted and receive treatment. Parity of esteem between mental and physical health care was enshrined in law in the England by the 2012 Health and Social Care Act (18). Mandating DMC assessments for those requiring admission to a psychiatric unit could be interpreted as going against this Act, section 2 (3) of the MCA (capacity cannot be established just by reference to a person's age, condition or aspect of his behaviour) and the first statutory principle of the MCA (everyone over the age of 16 should be assumed to have capacity). The question remains as to whether the requirement of admission to a psychiatric unit is enough to suggest one lacks capacity. Is it fair to expect that psychiatric facilities document these decisions for every admission when physical

health facilities do not?

PROFESSIONALS COMPLETING DOCUMENTATION

In England, a patient cannot be admitted to a psychiatric hospital against their will unless they are first assessed under the *Mental Health Act 1983* (MHA). This requires an assessment by three independent professionals: 2 doctors and an Approved Mental Health Professional (AMHP). The two doctors' role is to decide whether to make a recommendation that the patient needs to be in hospital. It is the AMHP that ultimately decides to detain the patient in hospital (provided both doctors make recommendations). 31 of the 49 patients in this sample were admitted under the MHA. No DMC documentation for admission reviewed in this study was completed by AMHPs. Instead it was completed by doctors after the decision for admission had already been made. The function of DMC assessment and documentation should primarily be to guide management and not simply an administrative chore to be completed after the event. Given that capacity assessments are time and decision specific, DMC documentation for admission completed in these circumstances does not capture the initial decision of whether to be admitted to hospital. There is a time delay until the assessment is conducted for what will then be a different decision – whether to remain admitted to hospital.

It is of note that all of the MCA documentation completed by consultants was rated as insufficient, despite the fact that consultant psychiatrists have high levels of training and experience in conducting such assessments. Previous studies have highlighted that "the accuracy and effectiveness of implementing the MCA is contingent upon sufficient staffing and resources" (19) and that use of the MCA is seen as additional paperwork (20). This result could therefore be a reflection of the high consultant workload contributed to by low junior doctor numbers and ongoing recruitment difficulties in England (21). A recent systematic review identified challenges for clinical staff in applying the MCA in everyday clinical practice and limited effectiveness of current education strategies. As a result there have been calls for education and active implementation (22). Delays in developing training and local policies, variable knowledge of the definition of DMC and factors that may trigger an assessment of DMC (22) could also explain our findings of poor quality documentation by nursing staff and junior doctors. It is also possible that our findings are a reflection that the demands of a mental health ward conflict with the way the MCA was intended to be used (in terms of the time needed for training, to perform the MCA assessment, reflect on and document it) (23).

MINIMUM INFORMATION

The MCA assessor must identify the minimum amount of relevant information a person must understand in order to make a decision. This is a challenge as the assessor must tailor the information to the patients' values and judge the amount of detail to provide (24). In general, a view is taken that the more complex and serious the decision, the higher the bar is set for decision making capacity (25). Case law has led to suggestions on the minimum amount of information required to be understood for someone to make a capacitous decision about admission (26) and treatment (27) (Box 1).

A similar study reports that just 26% of patients were given sufficient information in order to make a decision regarding admission (28). Admission to a psychiatric ward is not the same as admission to a general hospital ward. On a psychiatric ward in England, nurses can use a holding power to prevent an informal capacitous patient from leaving and the doors are nearly always locked. It is unclear what percentage of informal patients in this study were aware of these differences.

The decision of whether to take medication for physical as well as mental health conditions falls under the decision of whether to accept treatment. A large number of DMC documentation did not define what specific interventions or medications the term "treatment" encompassed. For example, the decision of whether to take warfarin requires a person to understand a very different complexity and quantity of information about risks, benefits and monitoring requirements than the decision regarding whether to take Senna. According to the MCA Code of Practice, these should be separate capacity assessments and require separate documentation. When considering the numbers of medications patients were taking in our sample (on average 6.3 physical health medications and 2.3 psychotropic medications per patient) this would be a considerable increase in work load for the ward team.

AUDIT CYCLE – THE NEXT STEP

These findings highlight that more training and guidance is needed to support clinicians in evidencing DMC. This is planned to be delivered at induction of new staff members and through regular mandatory training. Case law will be used to highlight the importance of detailed documentation. Previous studies have demonstrated improvements in documentation with a structured proforma (29). With this in mind, since this project, the local MCA1 form has been redesigned with prompts to describe options discussed with patients and information given. There are plans to repeat the audit following education and dissemination of these results.

Box 1
Minimum information suggested for the decision of whether to be admitted to a psychiatric ward (14)

1. The person will be admitted for care and treatment for a mental disorder
2. The doors to the ward will be locked
3. Staff are entitled to carry out property and personal searches
4. The person will expect to remain on the ward until seen by a doctor (at least 24 hours)
5. The person will be required to inform nursing staff whenever they leave, telling them where they are going and the time of return
6. Nursing staff may refuse to agree to them leaving the ward if they believe the person is at risk or could pose a risk to others
7. If the person leaves the ward without informing staff or does not return at the time they say the staff will contact the police
8. The person's description will be recorded by staff to enable the above
9. The consequences of not being admitted to the ward

Minimum information suggested for discussing treatment (27)

- Illness requiring treatment
- Nature of the treatment
- Purpose of the treatment
- Risks/side effects of the treatment
- Risks of not having the treatment

Alternative treatment options

LIMITATIONS

This study involved a small number of patients and professionals completing documentation from one hospital in England. Because of this, it is possible that the results presented here are not truly representative of the population of interest. The reviewers were scrutinising the work of their colleagues. Although all documentation was anonymised before being rated as sufficient or insufficient, it is possible that the rating process was not completely free from rater or confirmation bias.

FUTURE DIRECTIONS

For testamentary capacity (30), capacity to gift (31), marry (32) and litigate (33) more specific, contextual legal standards in the courts through common law are not replaced by the MCA (34). Having an equivalent for capacity to consent to admission and treatment similar to that described by Palmer et al (35) or an evidence based tool such as the MCAST (36) may make the requirements of DMC documentation more clear.

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Disclosures

The authors have no potential conflicts of interest to disclose.

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CASE NOTE: N V ROMANIA (APPLICATION NO. 59152/08, DECISION OF 28 NOVEMBER 2017)

ALEX RUCK KEENE*

I. INTRODUCTION

Is deprivation of liberty ever justified for reasons arising out of a person's disability? Whilst there was a long-standing consensus in both international and regional human rights law that it could be, the adoption of the UN Convention on the Rights of Persons with Disabilities ('CRPD') in 2006 may radically have changed the picture, Article 14(1)(b) CRPD providing that "*the existence of a disability shall in no case justify a deprivation of liberty*."

In *N v Romania*, the European Court of Human Rights ('ECtHR') addressed how it considered Article 5 ECHR is to be interpreted in light of Article 14 CRPD; the case also saw Strasbourg grappling with the question of what is to be done where a person no longer meets the criteria for detention but cannot be discharged because of a lack of adequate provision in the community. This note discusses both that case and, in the concluding section, the subsequent decision of the Grand Chamber of the ECtHR in *Rooman v Belgium.*[1]

II. BACKGROUND

On 29 January 2001, following the publication of an article in the national press and a programme broadcast on a national television channel, the Romanian police initiated a criminal prosecution against the applicant, N. He was charged with incest and sexual corruption of his two under-age daughters, aged 15 and 16. He was alleged to have had sexual intercourse with his elder daughter and forced both his daughters to be present while he was having sexual intercourse with his wife. On April 2001, he was admitted to a psychiatric hospital, a forensic medical report prepared in November 2001 finding that he suffered from chronic paranoid schizophrenia and lack of discernment, and recommending putting in place a programme of compulsory medical treatment. All but one of the criminal charges (that relating to sexual corruption) were not, ultimately, proceeded with by the prosecution, but in April 2002 Bucharest District Court No 6 upheld the medical detention order against him. He remained detained in different psychiatric hospitals for the next 16 years.

N's position underwent a formal (if not a substantive) change in 2016, when, on the basis of forensic medical reports which determined that he did not pose a risk of danger to society, but that it was inconceivable that he could be released to be subject to treatment in the community absent social support, a court ordered that he continue to be detained in psychiatric hospital, pending transfer to a specialised institution capable of providing proper living conditions and treatment. A further forensic report

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[1] Application no. 18052/11, decision of 31 January 2019.

in 2017 recommended replacing the detention measure with a compulsory medical treatment order [in the community] in view of the applicant's "*low level of dangerousness (while on treatment), compliance with the rules, absence of incidents,* [and] *the lengthy period of supervision*" (paragraph 70). This led to a further order for the replacement detention measure with a compulsory treatment order until the applicant had made a full recovery.

Clearly out of desperation, the applicant then asked to remain in psychiatric hospital until his social situation had been settled. As his lawyer noted in a further letter to the hospital, releasing N without adequate support "*would condemn him to vagrancy, destitution and the deterioration of his physical and mental health*" (paragraph 76).

Nothing happened in terms of movement, and N took his case to Strasbourg, complaining that his detention was arbitrary and unjustified, and was based solely on his mental disability, which he claimed was contrary to the requirements of the Court's case-law, to Article 14(1)(b) CRPD and to the decision of the Committee on the Rights of Persons with Disabilities in the complaint brought by Marlon James Noble against Australia.[2] He further challenged the failures of the Romanian authorities (both judicial and administrative) to take appropriate steps to secure his release at the point where it became clear to them that the forensic medical evidence did not justify his continued detention.

III. THE DECISION

A. Article 5(1)

As is now customary, the Strasbourg court did not merely cite the relevant domestic legislation (which made clear that a detention measure could only be imposed on a person if he poses a danger to society) but set out what it considered to be relevant provisions from other international documents. The UN documents cited by the court were:

> (a) Articles 13, 14 and 19 of the UNCRPD and the Guidelines on Article 14 noted above;
>
> (b) The 2016 decision on the complaint of Marlon James against Australia, in which the CRPD Committee had held (at paragraph 8.7) that:*[t]he author's detention was […] decided on the basis of the assessment by the State party's authorities of potential consequences of his intellectual disability, in the absence of any criminal conviction, thereby converting his disability into the core cause of his detention. The Committee therefore considers that the author's detention amounted to a violation of article 14 (1) (b) of the Convention according to which "the existence of a disability shall in no case justify a deprivation of liberty.*
>
> (c) The report presented in July 2005 by the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health to the UN Commission on Human Right following his visit to Romania from 23 to 27 August 2004,[3] and the report in April 2016 on Special Rapporteur on Human Rights and Extreme Poverty to the UN Human Rights Council on his mission to Romania from 2 to 11 November 2015,[4] both of which spoke of concerns at the centralised and institutionalised model of mental health care.

[2] Communication No. 7/2012, CRPD/C/16/D/7/2012 (10 October 2016), [2017] MHLR 215.
[3] E/CN.4/2005/51/Add.4
[4] A/HRC/32/31/Add.2

The court set out what is now a standard 'mantra' in relation to deprivation of liberty for purposes of Article 5(1)(e). This mantra has lengthened over time, to add not just the classic *Winterwerp* criteria,[5] but also the observation that:

> 145. … the detention of a mentally disordered person may be necessary not only where he needs therapy, medication or other clinical treatment to cure or alleviate his condition, but also where the person needs control and supervision to prevent him, for example, causing harm to himself or other persons (see *Hutchison Reid v. the United Kingdom*, no. 50272/99, § 52, ECHR 2003-IV, and *Stanev v. Bulgaria* [GC], no. 36760/06, § 146, ECHR 2012).

And the observation that:

> 146. … in certain circumstances, the welfare of a person with mental disorders might be a further factor to take into account, in addition to medical evidence, in assessing whether it is necessary to place the person in an institution. However, the objective need for accommodation and social assistance must not automatically lead to the imposition of measures involving deprivation of liberty. The Court considers that any protective measure should reflect as far as possible the wishes of persons capable of expressing their will. Failure to seek their opinion could give rise to situations of abuse and hamper the exercise of the rights of vulnerable persons. Therefore, any measure taken without prior consultation of the interested person will as a rule require careful scrutiny (see *Stanev*, cited above, § 153).

In *N*'s case, the court considered that the first *Winterwerp* criterion was clearly met, the "applicant having suffered from mental disorders confirmed by a whole series of forensic medical reports" (paragraph 149). The real question was whether N's illness:

> 149. … *was of a kind or degree warranting detention and whether, in the particular circumstances of the case relating to the findings of the latest forensic medical reports, the applicant's detention had been extended validly.* [149]

B. Detention prior to 2016

The Strasbourg court identified two distinct stages to the case. Prior to the recognition by the domestic courts in 2016 that N should no longer be subject to psychiatric detention, the focus of Strasbourg's attention was upon the thoroughness of the first periodic review of his detention in 2007, which occurred after the legislative amendments designed to consolidate the rights of persons with disabilities. This should have warranted:

> 150. …an extremely thorough and complete examination ought to have been conducted in order to ascertain whether the applicant's psychiatric disorder was of a kind and degree warranting detention.

In fact, the ECtHR concluded, this had not happened, and the domestic court had failed to "*conduct a thorough assessment of the aspect which was essential in deciding on the applicant's detention, that is to say his dangerousness*" (paragraph 155). Subsequent reviews were equally "*formalistic and superficial*," nor did the responses to appeals lodged by N provide any kind of clarification (paragraph 156). Finally, "*neither the medical authorities nor the court itself considered whether any alternative*

[5] I.e. that the person reliably be shown to be of unsound mind (on the basis of "objective medical expertise"); secondly, the mental disorder must be of a kind or degree warranting compulsory confinement; thirdly, the validity of continued confinement depends upon the persistence of such a disorder, following *Winterwerp v. the Netherlands*, 24 October 1979, Series A no. 33, at paragraph 39.

measures might have been implemented in the present case" (paragraph 157). The Strasbourg court therefore had little hesitation in finding that, at least since 2007, the detention was contrary to the requirement in Romanian domestic law that a detention measure can only be imposed on a person if he poses a danger to society (paragraph 158), devoid of any basis in law and hence contrary to Article 5(1)(e) (paragraph 161).

In a passage to which I will return, the court also observed (at paragraph 159) that the detention was also open to question:

> [p]articularly in the light of the provisions of Article 14 § 1 (b) CRPD, which lays down that the existence of a disability shall in no case justify a deprivation of liberty.

C. 2016 onwards

As the court observed (at paragraph 162), the findings of the forensic medical reports in 2015:

> presented the medical officers with a psychiatric and deontological dilemma as regards the applicant's possible release, given that the provisions of domestic law concerning detention measures required the detainee to pose a danger to society, which did not apply to the applicant.

Referring back to previous case-law,[6] the ECtHR observed (at paragraph 163) that it did not exclude the possibility that:

> the imposition of conditions could justify a deferral of a discharge found to be appropriate or feasible in domestic-law terms, it was of paramount importance that appropriate safeguards were in place so as to ensure that any continued detention was consonant with the purpose of Article 5 § 1 of the Convention.

In N's case, the Strasbourg court noted (at paragraph 166) that his release had been ordered (provisionally) in 2016 and (definitively) in 2017:

> in line with practices which have become quite common at the international level in recent years, geared to promoting, as far as possible, treatment and care for persons with disabilities in the community (see Article 19 CRPD […] above, the Guidelines of the Committee on the Rights of Persons with Disabilities [on Article 14 CRPD] above, the Council of Europe's Disability Strategy 2017-2023 […] and, mutatis mutandis, *W.D. v. Belgium*, no. 73548/13, § 113, 6 September 2016).

However, the blunt fact remained that N had never actually been released, nor had any thorough assessment had been carried out to date of the applicant's practical needs and the appropriate social protection measures. Furthermore, the action taken by the national authorities had been unproductive because of an internationally recognised lack of reception facilities in Romania.

The ECtHR therefore held that N's continued detention after 2016 was arbitrary for purposes of Article 5(1)(e) ECHR.

[6] *Luberti v. Italy* (23 February 1984, Series A no. 75); *Johnson v. the United Kingdom* (24 October 1997, *Reports of Judgments and Decisions* 1997-VII) and *Kolanis v. the United Kingdom* (no. 517/02, ECHR 2005-V).

D. Article 5(4)

The court had little hesitation in finding that Article 5(4) had been breached in N's case, on the basis of:

> (1) lengthy intervals between judicial determinations of the necessity of maintaining the applicant's detention, which did not meet the "speediness" requirement set out in Article 5(4) ECHR;
> (2) the inadequacy of the legal assistance provided him. The court noted that in the great majority of the hearings, the officially appointed lawyers either advocated the maintenance of the detention or left it to the discretion of the courts. The court professed not to be "*dictating how a lawyer should approach cases in which he or she represents a person suffering from mental disorders*" (paragraph 197), but it is clear that it took a dim view of the approach taken by N's lawyers, who were different at each stage, and who entirely failed to consult with him.

E. Remedies

Unusually, the Strasbourg court set out individual measures required in order to execute its judgment, in particular that the authorities should immediately implement the 2017 judgment ordering N's release under conditions consonant with his needs. Further, it noted that:

> the shortcomings identified in the present case are liable to give rise to further justified applications in the future. Accordingly, it recommends that the respondent State should envisage adopting the requisite general measures to ensure that the detention of individuals in psychiatric hospitals is lawful, justified and devoid of arbitrariness. Similarly, detainees should have access to a judicial appeal accompanied by appropriate safeguards ensuring a prompt decision on the lawfulness of the detention.

IV. COMMENT

A. Delayed discharge

The problem of delayed discharge from psychiatric hospitals does not just bedevil countries such as Romania. Whilst *N v Romania* does not represent a dramatic advance in the Strasbourg jurisprudence in relation to this issue, it provides further confirmation that the state is on very thin legal ice when it seeks to rely upon its own failings to provide adequate services in the community to justify the continued detention of a person under Article 5(1)(e) once they no longer meet the domestic criteria for psychiatric detention.

B. Deprivation of liberty – Article 5(1)(e) and the CRPD

As noted at the outset, Article 14(1)(b) CRPD makes clear that "*the existence of a disability shall in no case justify a deprivation of liberty*." Precisely what this implies, however, is hotly contested.

At the UN level, the UN Human Rights Committee (the treaty body for the International Covenant on Civil and Political Rights, which includes its own right to liberty) and the Committee on the Rights of Persons with Disabilities have given differing interpretations of Article 14(1)(b). Both Committees agree that deprivation of liberty

on the basis of disability alone is unlawful.[7] However, the two Committees differ as to whether it is ever permissible to deprive a person of their liberty to secure against risks to them or other people said to arise from their mental health condition (i.e. their disability).

The Committee on the Rights of Persons with Disabilities takes the view, expressed in 'Guidelines' in 2015 that "[t]*he involuntary detention of persons with disabilities based on risk or dangerousness, alleged need of care or treatment or other reasons tied to impairment or health diagnosis is contrary to the right to liberty, and amounts to arbitrary deprivation of liberty.*"[8] Subsequent to the decision in *N*, this view was echoed – in even stronger terms – by a report published in 2018 by the UN Special Rapporteur for Persons with Disabilities, Catalina Devandas.[9]

In General Comment No 35, the UN Human Rights Committee, conversely, expressed the view – which it sees as supported by Article 14(1)(b) CRPD – that "[t]*he existence of a disability shall not in itself justify a deprivation of liberty but rather any deprivation of liberty must be necessary and proportionate, for the purpose of protecting the individual in question from serious harm or preventing injury to others,"* and further that "[f]*orced measures must be applied only as a measure of last resort and for the shortest appropriate period of time, and must be accompanied by adequate procedural and substantive safeguards established by law.*"[10] A similar view was taken by the UN Human Rights Council Working Group on Arbitrary Detention ('WGAD') in the context of a complaint against Japan, [11] the Working Group noting that "*it is contrary to the provisions of article 14 of the Convention to deprive a person of his or her liberty on the basis of disabil*ity,"[12] and in relation to the specific facts of the detention of the individual in question that:

> 46. […] neither at the time of his detention nor prior to that there is any evidence of Mr. N being violent or otherwise presenting a danger to himself and/or to others. His subsequent transfer to Tokyo Metropolitan Matsuzawa Hospital had no connection to the initial incident of attempted theft. It is therefore clear to the Working Group that the deprivation of liberty of Mr. N was carried out purely on the basis of his psychiatric disorder, and was thus discriminatory. The Working Group therefore concludes that Mr. N's detention and his subsequent internment in Tokyo Metropolitan Matsuzawa Hospital and Koganei Hospital were discriminatory …. (emphasis added)

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[7] UN Human Rights Committee: General Comment No. 35 (2014), on Article 9 - Liberty and security of person, para 19; UN Committee on the Rights of Persons with Disabilities, 2015: "*Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities."* para 6. The differing views of relevant UN bodies as to involuntary detention and treatment are usefully summarised in Martin, W., & Gurbai, S.,'Surveying the Geneva impasse: Coercive care and human rights,' *International journal of law and psychiatry*, 2019: 64:117-128. See also by way of overview Fennell, P.W.H. and Khaliq, U., 'Conflicting or complementary obligations? The UN Disability Rights Convention, the European Convention on Human Rights and English law,' *European Human Rights Law Review*, 2011:6:662-674 and Bartlett, P.,'The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law,' *Modern Law Review*, 2012:75:752–778.

[8] UN Committee on the Rights of Persons with Disabilities, 2015: "*Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities."* para 13.

[9] Ending *the deprivation of liberty on the basis of disability*, available at www.embracingdiversity.net/report/Deprivation%20of%20liberty%20of%20persons%20with%20disabilitie 1030 (accessed 31 October 2019).

[10] UN Human Rights Committee: General Comment No. 35 (2014), on Article 9 - Liberty and security of person, para 19. See also A/HRC/36/37, para. 55; opinion No. 68/2017.

[11] A/HRC/WGAD/2018/8; opinion No. 8/2018.

[12] Citing in a footnote the UN Human Rights Committee General Comment on Article 9.

What had not been entirely clear until *N v Romania* would be whether the disagreement in Geneva would be echoed at Council of Europe level.

In 2016, in *Hiller v Austria*,[13] the ECtHR had considered a 2014 statement by the United Nations Office of the High Commissioner for Human Rights[14] predating but along very similar lines to the 2015 Guidelines from the Committee. The court did not expressly engage with the statement, as the case in question did not concern Article 5, but rather Article 2, in the context of a contention that the applicant's son had been able to commit suicide as a result of the psychiatric hospital's negligence. It did, though, have it in mind when it came to dismissing the claim, noting (in a passage that should serve as a powerful antidote to the 'risk aversion' model of mental health law[15]):

> 54 […] the hospital did not act negligently in allowing M.K. to take walks on his own once his mental state had improved after 2 April 2010. As evident from the international law sources pertaining to the issue [including the statement above] and as the Government has comprehensively argued, today's paradigm in mental health care is to give persons with mental disabilities the greatest possible personal freedom in order to facilitate their re-integration into society. The Court considers that from a Convention point of view, it is not only permissible to grant hospitalised persons the maximum freedom of movement but also desirable in order to preserve as much as possible their dignity and their right to self-determination.

The Council of Europe's former Commissioner for Human Rights, Nils Muižnieks, expressly endorsed the position of the Committee on the Rights of Persons with Disabilities in August 2017.[16]

Only a very few months later, however (and – perhaps deliberately – making no reference to the Commissioner's statement), the Strasbourg court in *N v Romania* confirmed that it interpreted Article 14(1)(b) CRPD in a different fashion. From the passage at paragraph 159 cited above, it is clear that the court interpreted Article 14(1)(b) CRPD in the same way as does the Human Rights Committee, as prohibiting deprivation of liberty solely on the basis of disability, but not excluding it as a necessary and proportionate response to secure a person of unsound mind against risk to self or others.

At the start of 2019, the Grand Chamber of the European Court of Human Rights returned to the subject in *Rooman v Belgium*[17], making the position even clearer. In this case, the central complaint under Article 5 was that the person detained on the basis of Article 5(1)(e) was not receiving appropriate treatment. The Grand Chamber took the opportunity to "clarify and refine the principles in its case-law" relating to Article 5 so as to be able to take account of the particular circumstances in which an individual is placed in compulsory confinement. The Grand Chamber considered that:

> 205 […] in the light of the developments in its case-law and the current international standards which attach significant weight to the need to provide treatment for the mental health of persons in compulsory confinement ([referring to the CRPD, the Guidelines on Article 14 CPRD the Recommendation REC (2004) 10 of the Committee of Ministers to member states concerning

[13] Application no. 1967/14, decision of 22 November 2016, [2018] MHLR 21.

[14] www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15183&LangID=E (accessed 15 January 2020).

[15] Which remains prevalent: see (in England and Wales): *Rabone & Anor v Pennine Care NHS Foundation* [2012] UKSC 2.

[16] https://www.coe.int/es/web/commissioner/-/respecting-the-human-rights-of-persons-with-psychosocial-and-intellectual-disabilities-an-obligation-not-yet-fully-understood (August 2017, accessed 15 January 2020).

[17] Application no. 18052/11, decision of 31 January 2019.

> the protection of the human rights and dignity of persons with mental disorders and explanatory memorandum (adopted on 22 September 2004)]), it is necessary to acknowledge expressly, in addition to the function of social protection, the therapeutic aspect of the aim referred to in Article 5 § 1 (e), and thus to recognise explicitly that there exists an obligation on the authorities to ensure appropriate and individualised therapy, based on the specific features of the compulsory confinement, such as the conditions of the detention regime, the treatment proposed or the duration of the detention. On the other hand, the Court considers that Article 5, as currently interpreted, does not contain a prohibition on detention on the basis of impairment, in contrast to what is proposed by the UN Committee on the Rights of Persons with Disabilities in points 6-9 of its 2015 Guidelines concerning Article 14 of the CRPD. (emphasis added)

The decisions in *N* and *Rooman* are hardly surprising, consonant as they are with the approach of member states to the ECHR. By way of example, the Republic of Ireland, which waited until 2018 to ratify the CRPD, until it had passed legislation designed to bring it into compliance with its obligations,[18] entered a declaration upon ratification of the CRPD – in full knowledge of the CRPD Committee's Guidelines – to the effect that

> "*it understand*[s] *that the Convention allows for compulsory care or treatment of persons, including measures to treat mental disorders, when circumstances render treatment of this kind necessary as a last resort, and the treatment is subject to legal safeguards*."

The decisions in *N* and *Rooman*, though, means that the 'impasse' at UN level noted by the UN Special Rapporteur in 2017 on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health is therefore now replicated at Council of Europe level.[19] The Grand Chamber in *Rooman* left the door open to a possible reinterpretation of Article 5 in due course by noting that it was proceeding on the basis of the "current" interpretation of the Article. It is certainly possible to see how it could in due course move to interpret Article 5(1)(e) ECHR as justifying deprivation of liberty only where the person not only has a mental disorder but that mental disorder renders them functionally incapable of making decisions about their care and treatment. However, not least because of the positive duty under Article 2 to secure the right to life of persons at real and immediate risk of suicide,[20] a duty which may – in extremis – need to be discharged by detaining the person,[21] it is difficult to see how the impasse will ever be fully bridged in legal terms.[22] Even a move to narrow the gap to those who are functionally incapable of decision-making at the relevant moment would not meet with the approval of the Committee who, to date, have challenged the validity of the concept of mental capacity.[23]

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[18] In particular, the Assisted Decision-Making (Capacity) Act 2015.

[19] See Dainius Pūras, "Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health" (2017) A/HRC/35/21, para 33.

[20] See most recently *Fernandes de Oliviera v Portugal* (Application 78103/14, decision of 31 January 2019).

[21] Although in *Fernandes de Olivieira*, the Grand Chamber recognised the balancing act in play here, reiterating "*that the very essence of the Convention is respect for human dignity and human freedom. In this regard, the authorities must discharge their duties in a manner compatible with the rights and freedoms of the individual concerned and in such a way as to diminish the opportunities for self-harm, without infringing personal autonomy (see, mutatis mutandis , Mitić v. Serbia , no. 31963/08, § 47, 22 January 2013). The Court has acknowledged that excessively restrictive measures may give rise to issues under Articles 3, 5 and 8 of the Convention (see Hiller* [Application no. 1967/14, decision of 22 November 2016*] § 55)*." (para 112).

[22] Although see, for possible ways forward, Martin, W., & Gurbai, S.,'Surveying the Geneva impasse: Coercive care and human rights,' *International journal of law and psychiatry*, 2019: 64:117-128.

[23] UN Committee on the Rights of Persons with Disabilities, 2014: "General Comment No. 1 on Article 12: Equal recognition before the law." CRPD/C/GC/1, para 14. But it is possible that this is changing –

If the legal impasse is unbridgeable, this means that the pressure is all the greater to find solutions which reduce the relevance of this impasse in practical terms – i.e. by reducing the need to invoke the requirements of Article 5(1)(e) in Council of Europe countries (or its broader equivalent in Article 9 ICCPR in other jurisdictions).[24]

the Concluding Observations on the second report of Australia (CRPD/C/AUS/CO/2-3, 15 October 2019) include a recommendation (at paragraph 24) that Australia adopt the recommendations set out in the Australian Law Reform Commission's 2014 report, 'Equality, Capacity and Disability in Commonwealth Laws' (ALRC Report 124). These recommendations are based, in part, upon a functional model of capacity.

[24] See, for instance, Gooding, P. et al, 'Alternatives to Coercion in Mental Health Settings: A Literature Review' available at https://socialequity.unimelb.edu.au/news/latest/alternatives-to-coercion (accessed 15 January 2020).

BOOK REVIEW: THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES IN PRACTICE: A COMPARATIVE ANALYSIS OF THE ROLE OF COURTS (EDITED LISA WADDINGTON AND ANNA LAWSON) (OUP, 2018).

ALEX RUCK KEENE*

This ambitious, multi-authored volume, explores how the UN Convention on the Rights of Persons with Disabilities (CRPD) has been given effect and interpreted by courts in 11 national jurisdictions and by two regional bodies (the Council of Europe and the European Union). This comprehensive study examines how courts in thirteen different jurisdictions make use of the Convention, and is the first sustained comparative international law analysis of the CRPD,

The first part of the book contains chapters specific to each jurisdiction. The second part consists of comparative chapters which draw on the analysis of the jurisdiction-specific chapters. These chapters reflect on emerging patterns of judicial usage and interpretation of the CRPD and on the wider implications for human rights theory and the nascent field of international comparative human rights law.

Importantly, and helpfully, the national jurisdictions in the first part of the book are drawn from across the globe, and include Argentina, Australia, India, Kenya, Mexico, alongside the European jurisdictions of Germany, Ireland, Italy, Spain and the United Kingdom, and Russia, a world unto itself. As the editors explain, these were selected because there had been at least five judgments in each jurisdiction which seriously engaged with the CRPD, and there was a suitably qualified Anglophone expert able to contribute.

In each of the chapters, the relevant author(s) provides a thumbnail sketch of the legal system of the jurisdiction in question, an explanation of the status of the CRPD within that system, a review of the use of the CRPD by the courts of that jurisdiction, and then an analysis of the way in which the relevant courts have interpreted the CRPD.

Unlike many such multi-jurisdictional works, the book also includes an expressly comparative section at the end, seeking to draw together comparative analysis of the interpretation of the CRPD in each of the 13 jurisdictions, examining the uses to which the CRPD is put by domestic courts.[1] I would draw particular attention to the chapter by Anna Lawson and Lisa Waddington addressing the interpretation of the CRPD on an article by article basis in the different courts, and the thoughtful chapter by Lisa Waddington on the role of the judiciary and its relationship to the CRPD. A final chapter by Christopher McCrudden seeks to place comparative

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[1] A term used by the editors to include the European Court of Human Rights ('ECtHR') and Court of Justice of the European Union ('CJEU').

international law scholarship in the context of human rights theory.

This book straddles multiple purposes and seeks to serve multiple audiences. It could be used both by practising lawyers seeking to run cases involving the CRPD before domestic (or regional) courts, and searching for inspiration from other jurisdictions. It could equally be used by students (albeit, given its hefty price-tag, sadly only students at well-resourced institutions) seeking to gain an understanding of the birth pangs of the CRPD as a living legal instrument, rather than political statement. It could also be used by those seeking to understand the CRPD as a very new, and different, approach to thinking about the very concept of human rights. All of these audiences will find themselves enriched, challenged and stimulated by the individual chapters and the editorial themes of the work as a whole. The chapter on interpreting the CRPD in domestic courts alone represents a major contribution to understanding how some of the key articles are beginning to take life in practice in courts across the world – above all Articles 5 (equality and non-discrimination) and 12 (the right to legal capacity).

Taking a step back, however, the overriding impression from the book is that it is a very open question as to whether the next edition will be able to point to more cases in which the CRPD has actually been interpreted in the fashion advocated for by the Committee on the Rights of Persons with Disabilities. Or will the CRPD be interpreted by domestic and regional courts in a very different fashion?

For these purposes, I focus on the question of Article 12 CPRD, as this has been the subject of some of the most active debates and judicial activity.[2] It has, further, been the focus of some of the most sustained activity on the part of the CRPD Committee. It is unfortunate that, given the cut-off for consideration of cases for the book – on varying dates in 2016 – those covered, especially those from the highest judicial bodies within the relevant jurisdiction, largely pre-dated the growing body of materials generated by the Committee through which it has set out its interpretation of Article 12.

At one level this fact is useful in terms of enabling the editors to be able to fit awkward cases into what is a clear thesis as to how Article 12 should be interpreted by domestic courts. Lawson and Waddington can, for instance, legitimately note that the decision of the Spanish Supreme Court[3] to the effect that plenary guardianship (i.e. the total deprivation of a person's legal capacity) was issued in 2009 *"in the early dates of the CRPD and before the guidance provided by General Comment No 1"*.[4]

However, at another level the timing of this first edition is unfortunate because, with

[2] The only one of the 13 jurisdictions covered in the book not to yield any substantive cases involving Article 12 being the CJEU; in Australia, Ireland, Kenya and Mexico, Article 12 was the provision receiving most interpretative attention.

[3] Civil Chamber of the Spanish Supreme Court, Judgment 282/2009 of 29 April 2009. They also note the judgment to similar effect of the Constitutional Court of the Russian Federation some three years later, *In Re Delova* (judgment of 27 June 2012, case 15-P).

[4] Lawson and Waddington, page 497.

one partial exception, the book cannot engage with the series of cases in which courts have (in different ways) taken issue with the CRPD Committee's interpretation of Article 12 and, in particular, the assertion that Article 12 requires the abolition of substituted decision-making regimes, in other words, regimes where:

> *(i) legal capacity is removed from a person, even if this is in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will; or [5] (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective "best interests" of the person concerned, as opposed to being based on the person's own will and preferences* [6]

This assertion has been the subject of extensive debate in academic and activist circles.[7] It is now, however, coming under sustained judicial scrutiny, albeit scrutiny that, for the most part, post-dates the cases considered in this work.

The partial exception is that of the decision of the German Federal Constitutional Court in relation to (in English terms) mental capacity and involuntary (physical) health treatment decided in July 2016.[8] The case was decided just too late for consideration in Valentin Aichele's country chapter, but Lawson and Waddington make brief note of it in their chapter on interpreting the CRPD in domestic courts.[9]

It would have been fascinating to have the case placed in its specifically German context (in which the CRPD has frequently been referred to at Federal court level). It would also have been very interesting to have the full force of the editors' combined intellect brought to bear on the passage from the judgment, cited without comment,[10] in which the Federal Constitutional Court specifically denied the authority of the CRPD Committee to:

> *develop international treaties beyond the scope of agreements and the practice of the States party to the treaty*.. [and held that] ..*Article 34 (et seq) of the CRPD does not give the Committee of the mandate to issue any binding interpretation of the text of the treaty*.

Although Lawson and Waddington do not specifically note this fact in their brief reference to this case, the German Federal Constitutional Court had regard to both

[5] The word "and" which appeared initially being an error, corrected in a corrigendum published on 26 January 2018, available at http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1/Corr.1&Lang=en (accessed 15 January 2020).

[6] UN Committee on the Rights of Persons with Disabilities, 2014: "*General Comment No. 1 on Article 12: Equal recognition before the law.*" CRPD/C/GC/1.

[7] An extremely useful summary of the debates can be found in chapter 2 of Piers Gooding, *A New Era for Mental Health Law and Policy* (Cambridge University Press, 2017).

[8] BVerfG, Order of 26 July 2016 – 1 BvL 8/15. This case is covered in detail in the November 2016 edition of the 39 Essex Chambers Mental Capacity Newsletter: http://www.39essex.com/content/wp-content/uploads/2016/11/MC-Newsletter-November-2016-Capacity-outside-the-Court-of-Protection.pdf (accessed 2 November 2018); an English language copy of the judgment is not available.

[9] Lawson and Waddington, pages 531-532.

[10] Lawson and Waddington, page 531.

the CRPD's General Comment 1 on Article 12,[11] and its 2015 Guidelines on Article 14,[12] the court considering that:

> *The UN Committee remained silent* [in General Comment 1] *with regard to the question that was relevant in the present case, namely medical emergencies in which the "free will" of a disabled person is completely absent.*
>
> *The court took the view that a corresponding approach applied to the guidelines of the Committee regarding the interpretation of Article 14 of the CRPD (of September 2015). In those guidelines the Committee had emphasised that no healthcare measures should be taken in respect of persons with disabilities that are not based on the free and informed consent of the person concerned. The Committee asserted that states should refrain from any form of compulsory treatment. However, the court held that here also the Committee had not provided an answer to the question of what, according to its understanding of the treaty provisions, should happen to persons who cannot form a "free will" and who are in a vulnerable position. The court held that, even taking into account the views of the UN Committee, there were no good reasons under the text and spirit of the CRPD to abandon such persons to their fate, and to conclude that the Convention is opposed to compulsory medical treatment where this is constitutionally required under strictly regulated circumstances.*[13]

The German Federal Court chose to find silence in the relevant materials from the CRPD Committee in order to reach this outcome was perhaps diplomatic, but in reality this represents a deliberate misreading of the very clear, uncompromising, message contained in both General Comment 1 and the Article 14 Guidelines.

In similar vein is the decision of the ECtHR in *AM-V v Finland*,[14] which came too late for Oliver Lewis's masterly chapter on the Council of Europe. The case concerned whether an individual subject to *"mentorship"*[15] should have been able to have his mentor removed because he would not allow him to move to live with his former foster family.

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[11] UN Committee on the Rights of Persons with Disabilities, 2014: "*General Comment No. 1 on Article 12: Equal recognition before the law.*" CRPD/C/GC/1.

[12] UN Committee on the Rights of Persons with Disabilities, 2015: "*Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities."*

[13] This is taken from Adrian Ward's report of the case in the Mental Capacity Law Newsletter November 2016: Issue 70 (39 Essex Chambers) www.39essex.com/content/wp-content/uploads/2016/11/MC-Newsletter-November-2016-Capacity-outside-the-Court-of-Protection.pdf (accessed 15 January 2020).

[14] Application no. 53251/13, decision of 23 March 2017.

[15] At paragraph 85, the ECtHR described the powers of the mentor thus: "*If, like in the present case, the court has specifically ordered that the mentor's function shall also cover matters pertaining to the ward's person, the mentor is competent to represent the ward in such a matter only where the latter is unable to understand its significance* […] *In a context such as the present one, the interference with the applicant's freedom to choose where and with whom to live that resulted from the appointment and retention of a mentor for him was therefore solely contingent on the determination that the applicant was unable to understand the significance of that particular issue. This determination in turn depended on the assessment of the applicant's intellectual capacity in conjunction with and in relation to all the aspects of that specific issue. The Court also notes that Finland, having recently ratified the UNCRPD, has done so while expressly considering that there was no need or cause to amend the current legislation in these respects (see Government Bill HE 284/2014 vp., p. 45)."*

The Strasbourg court had before it, and directly referenced, General Comment 1; it also had submissions from the Mental Disability Advocacy Centre[16] to the effect that:

> *The starting point, based on the current international standards, was that the will and preferences of a person with disabilities should take precedence over other considerations when it came to decisions affecting that person. This was clear from the text of the United Nations Convention on the Rights of Persons with Disabilities. Even in jurisdictions with a former reliance on the "best interests" approach, there was an emerging trend towards placing more emphasis on the will and preferences of the person. There was a clear move from a "best-interests" model to a "supported decision-making" approach. [67]*
>
> *The Centre noted that the Court had held on a number of occasions that guardianship systems constituted a very serious interference with a person's Article 8 rights. Article 8 § 2 of the Convention needed to be interpreted in a manner consistent with international standards, taking into account the international recognition of the importance of autonomy and supported decision-making for individuals with disabilities. Rights guaranteed in Article 2 of Protocol No. 4 to the Convention were closely intertwined with those of Article 8. Circumstances in which an interference would be justified were limited and had to be restrictively construed. Persons with disabilities needed to be able to choose where and with whom to live, and had to be given the opportunity to live independently in the community on the basis of their own choice and, on an equal basis with others. [68]*

Not only did the Strasbourg court take the view that mentorship did not deprive the person in question of their legal capacity,[17] it also endorsed an approach which – contrary to the position in General Comment 1 – was based upon both mental capacity[18] and substituted decision-making. Holding that the applicant's rights under Article 8 ECHR (the right to private and family life) had not been breached, the court used – deliberately – the language of Article 12(4) CRPD to reach conclusions that it is clear are entirely at odds with the Committee's interpretation of that Article:

> *The Court is mindful of the need for the domestic authorities to reach, in each particular case, a balance between the respect for the dignity and self-determination of the individual and the need to protect the individual and safeguard his or her interests, especially under*

[16] Now Validity; in something of an irony, Lewis was formerly the Executive Director.

[17] See paragraph 85: "[t]*urning to the present case, the Court notes that under Finnish law, the appointment of a mentor does not entail a deprivation or restriction of the legal capacity of the person for whom the mentor is designated (see paragraph 29 above).* […] *If, like in the present case, the court has specifically ordered that the mentor's function shall also cover matters pertaining to the ward's person, the mentor is competent to represent the ward in such a matter only where the latter is unable to understand its significance (see paragraph 30 above). In a context such as the present one, the interference with the applicant's freedom to choose where and with whom to live that resulted from the appointment and retention of a mentor for him was therefore solely contingent on the determination that the applicant was unable to understand the significance of that particular issue. This determination in turn depended on the assessment of the applicant's intellectual capacity in conjunction with and in relation to all the aspects of that specific issue. The Court also notes that Finland, having recently ratified the UNCRPD, has done so while expressly considering that there was no need or cause to amend the current legislation in these respects (see Government Bill HE 284/2014 vp., p. 45).*"

[18] See paragraph 85 and also paragraph 89: "*the decision was based on the finding that, in this particular case, the disability was of a kind that, in terms of its effects on the applicant's cognitive skills, rendered the applicant unable to adequately understand the significance and the implications of the specific decision he wished to take, and that therefore, the applicant's well-being and interests required that the mentor arrangement be maintained.*"

> *circumstances where his or her individual qualities or situation place the person in a particularly vulnerable position. The Court considers that a proper balance was struck in the present case: there were effective safeguards in the domestic proceedings to prevent abuse, as required by the standards of international human rights law, ensuring that the applicant's rights, will and preferences were taken into account. The applicant was involved at all stages of the proceedings: he was heard in person and he could put forward his wishes. The interference was proportional and tailored to the applicant's circumstances, and was subject to review by competent, independent and impartial domestic courts. The measure taken was also consonant with the legitimate aim of protecting the applicant's health, in a broader sense of his well-being. [90]*

Other courts around the world have followed suit,[19] a good example being the decision of the Supreme Court of Victoria in *PBU v Mental Health Tribunal and Melbourne Health; NJE v Mental Health and Bendigo Health*,[20] in the context of the lawfulness of the administration of electroconvulsive therapy to individuals lacking the mental capacity to give informed consent. Whilst formally avoiding a direct confrontation with General Comment 1, Bell J expressly cited (at paragraph 91) both the German Federal Constitutional Court decision in 1 BvL 8/15 and *A-MV* as evidence of courts disagreeing with the interpretation of Article 12; the judgment, further, proceeded on the basis that administering ECT to a person unable to consent to it was not, inherently, contrary to the CRPD.

All three of these cases were decided at least a decade after the Convention was adopted and cannot simply be dismissed as decided in the absence of guidance from the Committee. Do they represent the last gasp of an older conception of human rights that accepts the existence of a class of individuals in respect of whom – in the last resort – decisions must be taken? In that conception, the key questions, in human rights terms, are as to the safeguards that must be placed around those decisions. If they do represent this last gasp, is it safe to assume that as those wedded to that older conception retire, the newer model will simply take its place? Or do they represent a more concrete challenge to the assertions of the Committee: and, if so, how do those assertions stand up to the forensic analysis undertaken by the courts? And – if so – what strategies should advocates seek to persuade those courts to adopt the Committee's approach?

As above, I do very much hope that there will be a second edition of this book, in which we can get further answers to these questions. For the present, though, all those involved in the first edition are to be congratulated for what will undoubtedly in due course come to be seen as a seminal text in the 'operationalisation' phase of the CRPD's life.

[19] See, e.g. the obiter observations of Ellis J in *S v Attorney-General* [2017] NZHC 2629 in relation to the General Comment at paragraph 29: "*that its import would appear to be that treating those with intellectual disabilities differently from those without such disabilities will always be discriminatory, however beneficial or preferential such treatment might be. It certainly seems to run contrary to most States' parties understanding of the Convention, including New Zealand's*."
[20] [2018] VSC 564.

BOOK REVIEW: THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES: A COMMENTARY, EDITED BY ILIAS BANKETAS, MICHAEL ASHLEY STEIN AND DIMITRIS ANASTASIOU (OXFORD: OXFORD UNIVERSITY PRESS, 2018)

ALEX RUCK KEENE*

This edited multi-author volume falls into the category of essential but frustrating. It is essential because of what it represents, namely the attempt to provide detailed commentary upon each of the articles of the Convention on the Rights of Persons with Disabilities. The template for the commentary, sensibly, is identical for each article, including an outline of the background to the article, an overview of the negotiations leading to the final wording (in most cases including, but going beyond, the formal *travaux préparatoires*), and then an analysis of each of the material parts of the article. Where relevant, that analysis includes consideration of how the word(s) in question have been interpreted by the Committee on the Rights of Persons with Disabilities, the treaty body for the CRPD, in such documents as 'concluding observations' upon the reports of States Parties[1] and 'General Comments.'[2] The cut-off point for the text seems to have been the summer of 2017. This means that some authors have also in their chapters had the opportunity to cross-refer to *The UN Convention on the Rights of Persons with Disabilities: a comparative analysis of the role of courts* (Lisa Waddington and Anna Lawson, eds: Oxford, Oxford University Press, 2018), which stands as an important companion piece, looking at the way in which the Convention has been interpreted by domestic and regional courts.

Repeating the same format for each article means, inevitably, that there is a degree of repetition, especially in relation to the background sections within each chapter, but in fairness this is not a book that is intended to be read from cover to cover, but rather to be consulted on an article by article basis. But having (for the most part) a detailed discussion of the *travaux* for each article is extremely useful for purposes of developing arguments – whether academic or otherwise – about the interpretation of the articles in domestic jurisdictions, given the status that *travaux* have under the Vienna Convention on the Law of Treaties.[3] Further, the decision to include not just the 'substantive' articles, but also the procedural articles was a wise one. The commentary on the role of the Committee, in particular, is both interesting and important as the Committee continues to find its feet in establishing credibility with governments and courts alike.

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[1] I.e. the Committee's reports upon the compliance of States Parties with the obligations imposed by the Convention.

[2] I.e. the Committee's broader statements as to its interpretation of particular articles of the Convention.

[3] 1155 UNTS 331.

The editors, Ilias Banketas, Michael Ashley Stein and Dimitris Anastasiou, have pulled together a very wide range of contributors, and, to their credit, have not chosen solely contributors who uncritically seek to evangelise. As has become clear over the years since the CRPD came into effect, the simple message that it seeks to enshrine – i.e. to ensure that persons with disabilities are secured the opportunity to enjoy rights on an equal basis with others – is one that gives rises to real complexities. The best chapters in the book are the ones which seek to address those complexities and do not simply repeat the canard that the CRPD ushers in a 'new paradigm' (a term that appears over 100 times in the work). I would in particular single out the chapter on article 12, the right to legal capacity, by Dr Lucy Series and Anna Nilsson. Series and Nilsson are fortunate in that this is the article to which most attention has been devoted since the CRPD came into effect, so they have the most material, but Series in particular is careful to highlight that there are dilemmas in article 12 (and its interpretation by the Committee) that do not afford of easy resolution.

Why, then, do I start the review by saying that the book is frustrating? In part, this is because of some omissions. For instance, not all contributors get a biography at the start, which means that it is not possible to get an understanding on the face of the book as to their credentials and possible perspectives; it is also – perhaps – a shame that there is no overall introduction to the book beyond a very brief preface by the editors.

The book is also frustrating because – understandably for a multi-author volume – the quality of the chapters varies considerably. It is a particular shame that one of the weakest chapters is that on Article 14 CRPD, which does not examine in any detail the intensely fraught question of whether it prohibits detention in the presence of mental disorder, instead focusing on matters such as therapeutic jurisprudence; interesting, but largely irrelevant to the very pressing issues at hand. The commentary on Article 10 (the right to life) is also dominated by consideration of abortion to the detriment of consideration of such important matters about whether the positive obligation to secure the right to life justifies detention in some situations,[4] or how to approach decisions about life-sustaining treatment in relation to adults who lack capacity to give consent to that treatment. The limited discussion of life-sustaining treatment that there is, in turn, conflates medical assistance with dying and decisions about maintaining life-sustaining treatment, which are, in most jurisdictions, considered separately.

Any book will have omissions,[5] but it is frustrating that some of the thorniest issues in practice are ones that receive least attention in the commentary. There is no discussion, for instance, in the chapter of Article 17 (the right to integrity of the

[4] A justification which is well-recognised, for instance, within the regional framework of the European Convention on Human Rights: see, e.g. *Fernandes de Olivera v Portugal* (Application No. 78103/14, decision of 31 January 2019).

[5] One curious one is that the (sadly) short chapter on Article 13 (access to justice) by Dr Eilionoir Flynn makes no reference to her excellent book on precisely this subject: *Disabled Justice?: Access to Justice and the UN Convention on the Rights of Persons with Disabilities*. Routledge, 2016.

person) of how the doctrine of informed consent (of cardinal importance to the Committee) is to operate where a person has suffered a serious injury such that they are in a coma. The discussion in relation to Article 25 (the right to health) advances an idea of "supported informed consent," but, again, does not grapple with the position where, even with all possible support, a person is unable to give what could be recognised as informed consent. It may very well be that it is possible for treatment decisions to be made in such contexts on the basis of the "best interpretation" of the person's will and preferences (as per General Comment 1 on Article 12), but to suggest that this represents the operation of "informed consent" strains credulity.[6] The otherwise excellent commentary on Article 38 on the relationship between the Committee and other bodies is silent as to the tensions that are apparent in relation to compulsory treatment.[7]

The omissions noted above may well be telling insofar as they reflect strategic silences during the negotiation process in relation to matters of particular difficulty – although it could legitimately be said that it is a scholarly imperative to draw out these silences. They may also represent the fact that at least some of those with disabilities have found it difficult to have their voice heard – or, more troublingly – because those voices do not always say what some advocates want them to. It, is in particular, difficult to escape the feeling that this may be so in relation to those with dementia,[8] and it is perhaps of note there is no reference in the index (and only glancing references in the book) to this condition.

Notwithstanding these criticisms, however, this book will be required reference material for anyone seeking seriously to engage with the CRPD in its second decade. The editors are warmly to be congratulated for shepherding so substantial a work through to press.

[6] If the Committee considers admissible the complaint by Vincent Lambert's parents against France in relation to the decision to endorse the withdrawal of life-sustaining treatment (Mr Lambert then having died), it is possible that the Committee will then provide its authoritative view on this difficult subject. In the meantime, some thoughts about the interaction between Articles 10, 12, 17 and 25 can be found in Ruck Keene, A. and Lee, A. *Withdrawing life-sustaining treatment: a stock-take of the legal and ethical position,* J Med Ethics 2019;0:1–6. doi:10.1136/medethics-2019-105599. (https://jme.bmj.com/content/early/2019/09/05/medethics-2019-105599)

[7] See Martin, W., & Gurbai, S. (2019). Surveying the Geneva impasse: Coercive care and human rights. *International journal of law and psychiatry*, *64*, 117-128. (https://www.sciencedirect.com/science/article/pii/S0160252719300032)

[8] As to which, see Donnelly, M. (2019). Deciding in dementia: The possibilities and limits of supported decision-making. *International Journal of Law and Psychiatry*, *66*, 101466. (https://www.sciencedirect.com/science/article/abs/pii/S016025271930130X)