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Articles and Comment

Severe and Enduring *Anorexia Nervosa* in the Court of Protection in England and Wales

Analysing the Definition of Disability in the UN Convention on the Rights of Persons with Disabilities: is it Really Based on a 'Social Model' Approach?

Negotiating Relationality: Mental Capacity as Narrative Congruence

Some Continental European Perspectives on Safeguards in the Case of Deprivation of Liberty in Health and Social Care Settings

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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.

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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

Articles and Comment

This issue has been edited by:
Dr Darius Whelan (Lead Editor) and Professor Emma Cave

Editorial assistance has been provided by:
Hal Brinton

EDITORIAL

This issue of the IJMHCL is the third since the journal was relaunched in 2016. Since that time, the journal has received a steady stream of excellent submissions on mental health and/or mental capacity law from authors in various jurisdictions.

The intersection of mental health and mental capacity laws is at the heart of Emma Cave and Jacinta Tan's article, 'Severe and Enduring Anorexia Nervosa in the Court of Protection in England and Wales'. The article outlines the clinical uncertainties associated with prognosis and treatment of severe and enduring Anorexia Nervosa (SEAN). In five recent cases, the Court of Protection in England and Wales has been asked to consider the capacity and best interests of patients with severe and enduring Anorexia Nervosa. The article recommends that the courts adopt a patient-centred rather than clinician-centred approach to framing the decision that is subject to a capacity assessment. Where a patient with Anorexia Nervosa lacks capacity, reliance on their stated treatment preferences should be balanced with their views and hopes regarding prognosis. The value of different treatment options should be assessed in this light. The article warns that, given the clinical and ethical uncertainties regarding prognosis and appropriateness of treatment, there are dangers in relying on the same court-appointed expert in all cases. Kris Gledhill was the editor for this article.

The effects of the UN Convention on the Rights of Persons with Disabilities continue to extend across several jurisdictions. Katerina Kazou considers the definition of disability in the CRPD in her article, 'Analysing the Definition of Disability in the UN Convention on the Rights of Persons with Disabilities: Is it Really Based on a "Social Model" Approach?' The article argues that the definition of disability in the CRPD is closer to the definition provided in WHO's International Classification of Functioning, Disability and Health (ICF) than it is to the 'social model' of disability. The ICF understands disability as the multi-dimensional and interactive experience of a wide range of difficulties in functioning. In particular, these difficulties include impairments, limitations in performing activities and restrictions in participating in life situations, and arise out of the complex interaction between health conditions, personal factors and barriers in the physical and social environment. Kazou believes there could be positive effects in associating the CRPD with the ICF, as it can avoid the criticism faced by the 'social model' for its limitations, especially for considering impairment as being entirely irrelevant to the experience of disability. At the same time, the valuable insights of the 'social model' regarding the disabling effect of social and environmental barriers can be retained, but without ignoring the relevance of impairment to the experience of disability or minimising the health needs of persons with disabilities.

In his article 'Negotiating Relationality: Mental Capacity as Narrative Congruence', David Gibson argues that the concept of capacity that emerges from the Mental Capacity Act (2005) is conceptually flawed and places practitioners in an impossible situation regarding its application. He believes that the continued support by the UK government and others for the Act strengthens the idea that the capacity/incapacity distinction is natural and that incapacity is an intrapsychic feature of an individual. The paper proposes an alternative model for understanding capacity and its assessment based on a narrative theory that recognises the role of the practitioner and identity negotiation. The paper includes three principles of a narrative theory of capacity assessment:

> i) Mental Capacity determinations are judgements arising from and sometimes relating to an individual's personal identity but always in a relational dynamic.
>
> ii) What is assessed in mental capacity determinations is the congruence between the narrative account of events or behaviours of the assessor and the assessed.
>
> iii) The impetus to assess capacity begins where alternative accounts that can lead to narrative conflict are shared with or identified by an assessor of capacity.

In his article, 'Some Continental European Perspectives on Safeguards in the Case of Deprivation of Liberty in Health and Social Care Settings', Walter Boente addresses a dearth of comparative academic literature on deprivation of liberty in health and care settings across Europe. His article reviews relevant laws in Germany, Switzerland, France, Austria and Spain. He notes that there is a trend to emphasise the role of the judge, or at least an independent person, but there is no consensus as to whether the judge should play a role in the admission or control process. The judge does not replace the *medical* experts, but is considered a neutral, independent expert in *supervising* the decision making process. Boente notes that the impression remains that the continental European systems are based on a historically founded, objective, or sometimes paternalistic, perspective on deprivation of liberty. There might be differences between national laws, for example in their use of private or public law mechanisms, regarding the appointment of a representative for the person concerned, or even on the amount of information which the person must receive, but the systems remain patchwork, taking the wrong starting point. One outcome is that continental legislation struggles to address the requirements of the CRPD.

We would like to acknowledge the peer reviewers for their prompt and thorough comments, the proofreading assistance provided by Hal Brinton and the ongoing support of the library staff of Northumbria University.

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SEVERE AND ENDURING ANOREXIA NERVOSA IN THE COURT OF PROTECTION IN ENGLAND AND WALES

EMMA CAVE AND JACINTA TAN*

ABSTRACT

This article explores legal issues relating to the continuation of in-patient treatment for people with severe and enduring Anorexia Nervosa in circumstances where there are doubts as to treatment efficacy. In five recent cases, the Court of Protection in England and Wales has been asked to consider the capacity and best interests of patients with severe and enduring Anorexia Nervosa. Drawing upon international comparisons, this article outlines the clinical uncertainties associated with prognosis and treatment and evaluates legal assertions surrounding capacity and best interests. It is suggested that to ensure palliative management is based on need rather than diagnosis, and that capacity is decision- and not disease-specific, a closer alignment is required between the focus of any capacity and best interests assessments.

Three specific recommendations are put forward: Firstly the courts should adopt a patient-centred rather than clinician-centred approach to framing the decision that is subject to a capacity assessment. Secondly where a patient with Anorexia Nervosa lacks capacity, reliance on their stated treatment preferences must be balanced with their views and hopes regarding prognosis. The value of different treatment options should be assessed in this light. Thirdly given the clinical and ethical uncertainties regarding prognosis and appropriateness of treatment, there are dangers in relying on the same court-appointed expert in all cases.

I. INTRODUCTION

This paper considers medico-legal developments encompassing the treatment of people with severe and enduring Anorexia Nervosa (referred to in this paper by the acronym SEAN). Clinicians have only recently begun to use the term 'SEAN'.[1] There is disagreement as to when Anorexia Nervosa might usefully be labelled 'severe and enduring', what this means in terms of prognosis, and the consequences regarding treatment and management that flow from application of the label. This paper focuses on ways in which the law has in the past, and possibly might in future, resolve disputes about the care and treatment of patients with SEAN. There is growing recognition that

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We are most grateful to Alex Ruck Keene for comments on a previous draft, and to the anonymous reviewers. We also acknowledge the input of attendees of the Advanced Seminar at the Collaborating Centre for Values-Based Practice in Health and Social Care, University of Oxford: 'Can Anorexia Nervosa ever be a Terminal Illness?' on Monday 8th May 2017 where aspects of this paper were presented.

[1] A term used in Mitchison D, Hay P, Engel S, Crosby R, et al. 2013. Assessment of quality of life in people with severe and enduring anorexia nervosa: a comparison of generic and specific instruments. BMC Psychiatry. 13: 1-9. Also referred to as SEED-AN: see Robinson PH, Kukucska R, Guidetti G, Leavey G. 2015. Severe and enduring anorexia nervosa (SEED-AN): a qualitative study of patients with 20+ years of anorexia nervosa. European Eating Disorders Review 23(4): 318-26.

treatment of SEAN can in some cases be considered futile,[2] in which case there is no legal basis to impose it on patients who cannot or will not consent. Patients with SEAN do not have a disorder of consciousness and can usually articulate their current views. This paper considers what reliance should be placed on those views both in determining whether a patient (who will be called 'P' in this paper) with SEAN has capacity and, where capacity is lacking, assessing P's best interests.

In England and Wales, section 1(5) of the Mental Capacity Act 2005 requires that where a person lacks capacity, decisions made on their behalf must be in their best interests. Section 4 sets out factors that must be considered in this assessment and whilst there is no legislative hierarchy within its provisions, the facts of each case will determine that some factors have particular weight. The UK Supreme Court decision of *Aintree University Hospitals NHS Foundation Trust v James* (*Aintree*) established that best interests must be determined from the perspective of the person who lacks capacity.[3] Notwithstanding this development, the Law Commission reported in 2017 that the legal framework insufficiently prioritises the person's wishes and feelings.[4] Decision-makers should not merely 'consider' wishes and feelings, but should 'ascertain' them as far as is practicable and give them weight, departing from them only where it is necessary and proportionate to do so.[5] We argue that legal developments on the treatment of patients with SEAN fail to take a sufficiently patient-centred approach.

The article begins with a brief clinical account of treatment options for Anorexia Nervosa and the difficulties in recognising, labelling and treating severe and enduring cases. We then examine a series of five recent legal cases in which the respective judges advanced compassionate evaluations of whether compulsory treatment of patients with SEAN and other conditions should continue. The cases were heard in the Court of Protection, which has jurisdiction over financial and welfare matters for people who lack mental capacity. There follows an analysis of capacity, best interests and futility, and a proposal for greater alignment of the capacity and best interests assessments. The authors respectfully make three recommendations for future cases involving patients with SEAN. Though focussed on the Court of Protection, the recommendations flow from an analysis of universal principles of human rights and have resonance for international jurisdictions:

(1) The courts should take a patient-centred rather than clinician-centred approach to framing the decision that is subject to a capacity assessment. Whilst Anorexia Nervosa sometimes affects decision-making capacity in relation to nutrition, this does not preclude a finding that the patient has sufficient capacity regarding end of life decisions.

(2) Where a patient with Anorexia Nervosa lacks capacity, reliance upon their stated treatment preferences must be balanced with their views and hopes regarding prognosis. The value of treatment options should be assessed in this light.

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[2] Westmoreland P, Mehler PS. 2016. Caring for Patients with Severe and Enduring Eating Disorders (SEED): Certification, Harm Reduction, Palliative Care, and the Question of Futility. Journal of Psychiatric Practice Jul;22(4): 313-20.

[3] *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [45].

[4] Law Commission. 2017. Mental capacity and deprivation of liberty. Law Com No 372, 14.7.

[5] Ibid 14.16 – 14.18 and rec 40; Draft Bill, cl 8(2) and (3).

(3) Given clinical and ethical uncertainties regarding prognosis and appropriateness of treatment, courts should appoint experts from a broad pool. There are dangers of relying on the same appointed expert in all cases.

II. SEVERE AND ENDURING ANOREXIA NERVOSA

Anorexia Nervosa is a serious and potentially life threatening mental health condition. Whilst it typically affects adolescents, it can also affect children and people into middle age,[6] and, whilst many people who have Anorexia Nervosa are female, it also affects men. Voluntary treatment on an outpatient basis is often effective, but more serious cases may be referred to and treated by specialist eating disorder clinics and some of these people require hospitalisation. There is variation in the treatment and management of eating disorders within the NHS, there are chronic bed shortages[7] and patients are not always admitted to the appropriate treatment setting.[8]

Where P's health or survival is threatened, P may be detained under sections 2 or 3 of the Mental Health Act 1983 (MHA). Section 63 of the MHA allows medical treatment for the disorder, without consent, including artificial nutrition.[9] The most straightforward and common method of refeeding a patient is by gradually increasing the number of calories in an oral diet under supervision. For most patients, the requirement and expectation to eat, especially under the MHA, is sufficient. However, a small proportion of patients are unable to eat normally and require medically invasive feeding such as enteral nutrition, tube feeding. This carries its own risks, such as accidental feeding into the lung. This method of fluid and nutrition intake is sometimes acceptable to, preferred or even welcomed by patients with Anorexia Nervosa, as it limits choice and the burden of responsibility by bypassing the physical act of eating.[10] For others, however, there can be efforts to refuse, manipulate or remove the tubes, which is dangerous. If resistance is sustained, this can lead to increasing conflict and restraint which consequently can then raise the spectre of forced feeding under physical restraint or pharmacological sedation.

Refeeding through any means can lead to complications. Sustained malnutrition leads to deficiencies of both macronutrients (such as carbohydrates and protein) and micronutrients (such as vitamins and minerals). Refeeding rapidly by any means without proper medical supervision can lead to potentially life-threatening metabolic

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[6] Micali N, Martini MG, Thomas JJ, et al. 2017. Lifetime and 12-month prevalence of eating disorders amongst women in mid-life: a population-based study of diagnoses and risk factors. BMC Medicine [Online] 15:12. See http://dx.doi.org/10.1186/s12916-016-0766-4.

[7] See for example National Health Executive. 2016. National bed shortages force English anorexia patients to Scotland for care. 12th December. See http://www.nationalhealthexecutive.com/Health-Care-News/bed-shortages-force-english-anorexia-patients-to-scotland-for-care. And see proposals to tackle out-of-area placements for children and young people in Mental Health Taskforce. 2016. Five Year Forward View for Mental Health. See https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf.

[8] The Royal Colleges of Psychiatrists, 2014. Physicians and Pathologists. MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa. 2nd Edn. CR189, p 6. See http://www.rcpsych.ac.uk/files/pdfversion/CR189.pdf.

[9] *B v Croydon District HA* (1992) 22 BMLR 13, CA; *Re KB (adult) (mental patient: medical treatment)* (1994) 19 BMLR 144; *Riverside Health NHS Trust v Fox* [1994] 1 FLR 614; Office of the Public Guardian. 2013 (updated 2016). MCA Code of Practice, 9.26.

[10] See Tan J, Stewart A, Fitzpatrick R, Hope T. 2010. Attitudes of patients with anorexia nervosa to compulsory treatment and coercion. International Journal of Law and Psychiatry 33(1): 13-19.

changes, such as 'refeeding syndrome'.[11] Medical opinion differs as to the acceptability and efficacy of tube feeding voluntary patients. In some patients with Anorexia Nervosa, non-oral nutrition under varying degrees of compulsion may be the only option to maintain life. Naso-gastric tubes can be passed through the nose into the stomach; this is the commonest form of tube feeding but is only recommended for short periods. There are other forms of tube feeding such as Percutaneous Endoscopic Gastrostomy (PEG) feeding where a tube is surgically inserted into the stomach; or intravenous nutrition.

Eating disorders have the highest mortality rate of psychiatric disorders.[12] Approaches and treatments for Anorexia Nervosa are constantly evolving,[13] but severe Anorexia Nervosa is amongst the most challenging mental health conditions to treat.[14] Guidance from the Royal College of Psychiatrists[15] focuses on reducing fatal outcomes, recognising that they sometimes result from 'inappropriate palliative care'.[16] In 1997 the media reported the death of Nikki Hughes who had Anorexia Nervosa, stating that the NHS Trust treating her was given legal advice that her refusal of treatment could not be overridden.[17] The MHA Commission issued guidance to the contrary,[18] but reports of underfunding and confusion about the legal position persist.[19] Some patients are not given access to the right support at the right time. It is noteworthy that neither the 2004[20] nor the replacement 2017 guidance[21] issued by The National Institute for Health and Care Excellence (NICE) comments on the relevance of palliative management of Anorexia Nervosa, the emphasis being on timely and consistent treatment. As we shall see, future guidance may need to respond to developments in

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[11] NICE. 2006. Nutrition support in adults. Clinical guideline CG32.

[12] Arcelus J, Mitchell AJ, Wales J et al. 2011. Mortality rates in patients with Anorexia Nervosa and other eating disorders: A Meta-Analysis of 36 Studies. Archives of General Psychiatry 68: 724-31.

[13] See for example Park RJ, Singh I, Pike AC, Tan JO. 2017. Deep Brain Stimulation in Anorexia Nervosa: Hope for the Hopeless or Exploitation of the Vulnerable? The Oxford Neuroethics Gold Standard Framework. Frontiers in Psychiatry. 8: 44.

[14] Steinhausen HC. 2002. The outcome of anorexia nervosa in the 20th century. American Journal of Psychiatry 159:1284-93; Goddard E, Hibbs R, Raenker S, et al. 2013. A multi-centre cohort study of short term outcomes of hospital treatment for anorexia nervosa in the UK. BMC Psychiatry 13: 287.

[15] Royal College of Psychiatrists. 2014. Management of Really Sick Patients with Anorexia Nervosa' (MARSIPAN) CR198. And see Junior MARSIPAN: Management of Really Sick Patients under 18 with Anorexia Nervosa. CR168.

[16] Ibid, p 30.

[17] See Cooper G. 1997. Doctors get right to force-feed anorexic patients. The Independent. 5 August.

[18] Mental Health Act Commission. 2004. Guidance on the Treatment of Anorexia Nervosa under the Mental Health Act 1983. See http://www.seedeatingdisorders.org.uk/pdfs/user/F3774357-49CE-5BCB-F9BB-22ECC4C430E5.pdf.

[19] See The Masked AMHP. 2010. Anorexia, the Mental Health Act – and Kayleigh. See http://themaskedamhp.blogspot.co.uk/2010/12/anorexia-mental-health-act-and-kayleigh.html; BBC News. 2004. Anorexia death to be investigated. 4 February: See http://news.bbc.co.uk/1/hi/health/3460189.stm; Daily Mail. 2010. 'Skeletal' male chef suffering from anorexia and bulimia died while on daily diet of just two crackerbreads. 29 June: See http://www.dailymail.co.uk/news/article-1290635/Skeletal-male-chef-suffering-anorexia-bulimia-died-daily-diet-just-crackerbreads.html; Tyler J. 2016. Eating disorders nurse died weighing 5st after using her know-how to hide her own anorexia. Birmingham Mail, 24 October: See http://www.birminghammail.co.uk/news/midlands-news/eating-disorders-nurse-died-weighing-12072468; BBC News. 2017. Anorexic woman's death 'would have been prevented' with better treatment. 2 February. See http://www.bbc.co.uk/news/uk-england-devon-38825643.

[20] NICE. 2004. Eating disorders: core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. Clinical Guideline CG 9.

[21] NICE. 2017. Eating Disorders: Recognition and Treatment. NG69.

the classification of Anorexia Nervosa that could lead to a growing acceptance of palliative management in the most severe and enduring presentations.

As outlined above, the responses to treatment for Anorexia Nervosa are varied and multi-faceted. Attempts to differentiate between types or stages of Anorexia Nervosa are relatively new. The term 'Severe and Enduring' has traditionally been reserved for certain mental health conditions typically characterised by psychosis but more recently has been applied so as to describe a classification of particularly durable Anorexia Nervosa.[22] Hay and Touyz argue that the conceptualisation of staging models of Anorexia Nervosa has utility in assessment and treatment[23] but the staging of Anorexia Nervosa is not universally accepted[24]. A variety of labels are used to denote an enduring form of Anorexia Nervosa[25] and the prognosis for patients who fall into this category is under-researched.[26]

Ongoing analysis is needed to determine whether 'staging' of Anorexia Nervosa might or should lead to a greater acceptance of the withdrawal of active treatment in favour of purely palliative management of SEAN.[27] Questions around the suitability of palliative management in severe Anorexia Nervosa are hardly novel,[28] but its use has traditionally been determined by need rather than diagnosis. More recently, there have been calls for the palliative management of cases lasting more than ten years,[29] yet a recent longitudinal study found that around half of those who had not recovered from Anorexia Nervosa at 9 years, had recovered at 22 years.[30] From a clinical perspective at least, the study indicates that *routine* palliative management of SEAN is inappropriate.[31] It also raises questions surrounding the ongoing treatment of the third of patients studied who were not recovered at 22 years. There is little data on treatment efficacy in such cases. Nor is it clear that clinicians can distinguish the longstanding patients who eventually recover from those who will not. Some argue that treatment

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[22] Hay PI, Touyz S. 2015. Treatment of patients with severe and enduring eating disorders. Current Opinion in Psychiatry 28(6): 473-7.

[23] Touyz S, Hay P. 2015. Severe and enduring anorexia nervosa (SE-AN): in search of a new paradigm. Journal of Eating Disorders 3: 26.

[24] Maguire S, LeGrange D, Surgenor L et al. 2008. Staging anorexia nervosa: conceputalizing illness severity. Early Intervention in Psychiatry 2(1): 3-10.

[25] Wildes JE, Forbush KT, Hagen KE et al. Characterizing severe and enduring anorexia nervosa: An empirical approach. International Journal of Eating Disorders 50(4):389-397; Broomfield C, Stedal K, Touyz S, Rhodes P. 2017. Labeling and defining severe and enduring anorexia nervosa: A systematic review and critical analysis. International Journal of Eating Disorders 50(6): 611-623; 2017.

[26] Hay PJ, Touyz S, Sud R. 2012. Treatment for severe and enduring anorexia nervosa: a review. Aust N Z J Psychiatry. 46: 1136–44. And see Touyz S, Le Grange D, Hay P, Lacey H (Eds). 2016. Managing Severe and Enduring Anorexia Nervosa: A Clinician's Guide. London: Taylor and Francis.

[27] Treasure J, Stein D, Maguire S. 2015. Has the time come for a staging model to map the course of eating disorders from high risk to severe enduring illness? An examination of the evidence. Early Intervention in Psychiatry 9**:** 173–184.

[28] Williams CJ. 1998. Does palliative care have a role in treatment of anorexia nervosa? BMJ 317(7152): 195–197.

[29] See Steinhausen HC. 2002. The outcome of anorexia nervosa in the 20th century. American Journal of Psychiatry 159:1284-93.

[30] Eddy KT, Tabri N, Thomas JJ, et al. 2016. Recovery from Anorexia Nervosa and Bulimia Nervosa at 22-Year follow-up. Journal of Clinical Psychiatry Dec 20. doi: 10.4088/JCP.15m10393: 31.4% of anorectic patients recovered in 9 years and 62.8% in 22 years.

[31] The study focussed on patients with DSM-III-R/DSM-IV anorexia nervosa or bulimia nervosa.

should endure providing it is not rendered unviable by co-morbidities[32] while others adopt the stance that SEAN can be a terminal condition, in which case palliative management is appropriate.[33] Depending on the viewpoint, compulsory treatment against P's wishes can thus be viewed as either ethically imperative or ethically unjustifiable.

Moves to reclassify some cases of SEAN as terminal are influenced by human rights developments protecting rights to individual autonomy and freedom from discrimination. The five cases discussed below each referred to the European Convention on Human Rights, the jurisprudence of which is influenced by the UN Convention on the Rights of Persons with Disabilities 2006 (CRPD),[34] though disappointingly the cases do not expressly reference the CRPD. The UN CRPD prohibits discrimination based on disability (article 4); states that the existence of disability does not justify deprivation of liberty (article 14); and protects the rights of persons with disability to 'enjoy legal capacity on an equal basis with others in all aspects of life' (article 12). Although the UK ratified the Convention in 2009, it remains unincorporated in English law, and it clashes with aspects of the MHA 1983 and the Mental Capacity Act 2005, that apply in England and Wales.[35]

The paternalistic 'compassionate intervention' model[36] that sanctions compulsory refeeding for the good of the patient, gained credence on the basis of evidence that many patients who were coerced are later grateful for the intervention.[37] This model is losing force.[38] Draft NICE guidance charted a withdrawal of 'moral authority' for compulsory refeeding and the dawn of a 'more lenient approach'.[39] This development is not restricted to eating disorders. Consider recent proclamations that mental health units should supply sterile cutting equipment to some patients who self-harm on the basis that compulsion can exacerbate the problem. Sullivan argues for a harm minimisation model that recognises the value of supporting autonomy and independence.[40] As in cases of SEAN, the tensions are multi-faceted. Clinicians must

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[32] Collins Lyster-Mench L. 2016. There is no such thing as 'late terminal anorexia-nervosa'. Huffington Post 12 August. See http://www.huffingtonpost.com/entry/there-is-no-such-thing-as-late-terminal-anorexia-nervosa_us_5849c4e9e4b07d4bc0fa2605.

[33] See Schmidt S. 2016. Anorexic woman weighing 69 pounds has a right to starve, court rules. Washington Post 22 November: See https://www.washingtonpost.com/news/morning-mix/wp/2016/11/22/anorexic-woman-weighing-69-pounds-has-a-right-to-starve-court-rules/?utm_term=.08d50a6ef4ca, discussed below. AG was said to have 'late terminal anorexia nervosa'.

[34] See for example *Glor v Switzerland* (App. No.13444/04) (30 April 2009) and, more recently, *Çam v Turkey* [2016] ECHR 206 (23 February 2016).

[35] See Szmukler G, Daw R, Callard F. 2014. Mental health law and the UN Convention on the rights of persons with disabilities. International Journal of Law and Psychiatry 37(3): 245-252.

[36] Faith KE. 2002. Addressing Issues of Autonomy and Beneficence in the Treatment of Eating Disorders. National Eating Disorder Information Centre. See http://nedic.ca/sites/default/files/ addressing-issues-beneficience-and-autonomy-treatment-eating-disorders.pdf.

[37] Watson T, Bowers W and Anderson A. 2000. Involuntary Treatment of Eating Disorders. American Journal of Psychiatry 157: 1806-1810.

[38] Law Commission. 2017. Mental Capacity and Deprivation of Liberty. Law Com No 372, 13.18.

[39] NICE. Draft: Eating Disorders - Recognition and Treatment. [GID-CGWAVE0703] p 31; See resulting guidance: NICE. 2017. Eating Disorders: Recognition and Treatment. NG69.

[40] Sullivan PJ. 2017. Should healthcare professionals sometimes allow harm? The case of self-injury. Journal of Medical Ethics. Published Online First: 09 February 2017. doi: 10.1136/medethics-2015-103146. Contrast Pickard H, Pearce S. 2017. Balancing costs and benefits: a clinical perspective does not support a harm minimisation approach for self-injury outside of community settings. Journal of Medical Ethics. Published Online First: 09 February 2017. doi: 10.1136/medethics-2017-104152.

balance the patient's preferences against their insight into the condition; the value of independence and control against compulsion; long-term against short-term harm minimisation; and management against cure. A plurality of views exists as to the prognosis and treatment options of patients with SEAN and yet in the five cases discussed in the next section, the court called each time on the specialist advice of the same expert: Dr Tyrone Glover. Whilst there is nothing whatsoever to suggest that this advice was not of the highest quality and integrity, it is respectfully submitted that the court would benefit from consideration of a broader range of clinical viewpoints.

III. THE CASES OF E, L, X, W AND Z

All of the five cases involved female patients over the age of 18[41] who had suffered from Anorexia Nervosa for more than 14 years.[42] In each case, a determination of the patients' best interests was made on the basis that they lacked capacity to decide.

Only in *Re E* did the court decide that in-patient treatment should continue. This was also the only case in which the judge referred to the term 'withdrawal of life-sustaining treatment'.[43] Nonetheless, in the cases of L, X, W and Z, none of the judges avoided the reality that they were in effect choosing between end of life options.[44]

In the cases of L, X, W and Z, declarations were granted to the respective NHS Trusts allowing in-patient treatment to be withdrawn. The judges found there to be no available treatment offering a realistic prospect of significantly extending the patients' lifespans.[45] It was in each patient's best interests to be discharged from the MHA framework[46] in the hope that P would engage in voluntary treatment. Because that hope was negligible, the judges focussed on the inefficacy of continued compulsory treatment, considering the significant psychological and physical burdens it would entail. The patients were likely to resist refeeding by naso-gastric tube, so that restraint would be required. Taking each case in turn:

Re E (medical treatment: anorexia) [2012][47]

E was being treated in a palliative care setting, as previous treatment attempts had failed to affect a cure. The Official Solicitor and local authority sought a declaration that E be moved to an intensive care unit for refeeding. E's parents disagreed, arguing that palliative management was what E wanted. Peter Jackson J held that E lacked capacity to make decisions about life-sustaining treatment and that it was in her best

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[41] E was 32; L was 29; X a 'young woman'; W was 28; and Z was 46.

[42] E for 21 years; L for 15 years, X for 14, W for 20 and Z for 31 years.

[43] *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [5].

[44] *The NHS Trust v L and Others* [2012] EWHC 2741 (COP), [52] per Eleanor King J; *A NHS Foundation Trust v Ms X (Official Solicitor)* [2014] EWCOP 35, [44] per Cobb J; *Re W (medical treatment: anorexia)* [2016] EWCOP 13, [54] per Peter Jackson J; *Cheshire & Wirral Ptnr NHS FT v Z* [2016] EWCOP 56, [11] per Hayden J.

[45] *The NHS Trust v L and Others* [2012] EWHC 2741 (COP), [1], [7] per Eleanor King J; *A NHS Foundation Trust v Ms X (Official Solicitor)* [2014] EWCOP 35, [43] per Cobb J; *Re W (medical treatment: anorexia)* [2016] EWCOP 13, [49] per Peter Jackson J; *Cheshire & Wirral Ptnr NHS FT v Z* [2016] EWCOP 56 [9] per Hayden J.

[46] The procedural issues this raises are beyond the scope of this article but see *Cheshire & Wirral Ptnr NHS FT v Z* [2016] EWCOP 56, [21] per Hayden J.

[47] [2012] EWHC 1639 (COP).

interests to be forcibly re-fed. The 20-30%[48] chance of a full recovery that a 12-month (plus) programme of treatment might bring, justified any violation of her rights under Articles 3 and 8 of the European Convention on Human Rights. There was still hope for E:

> We only live once – we are born once and we die once – and the difference between life and death is the biggest difference we know. E is a special person, whose life is of value. She does not see it that way now, but she may in future.[49]

Sadly, there was evidence in *Re E* that E took pride in being 'the most treatment-resistant patient they had ever had'.[50] In *A NHS Foundation Trust v X* it was noted that, two years on, E was still receiving treatment as an in-patient.[51]

E had twice made advance decisions refusing refeeding. The validity of an advance decision turns on evidence that the maker had capacity at the relevant time. A doctor had opined that E had the requisite capacity, but soon after felt that E was not expressing a consistent wish to die. In an apparent reversal of the burden of proof, Peter Jackson J concluded that, on the balance of probabilities, E lacked capacity at the time she signed the advance decision.[52]

In its manner of presentation to the court, *Re E* differs from the other four cases. In *Re E* the Official Solicitor proposed continued treatment whereas in the other cases, the request was specifically about withdrawal of compulsory in-patient treatment. The open-endedness of the application in *Re E* did not go unnoticed. Peter Jackson J made clear that the court should not 'be drawn into theorising' but rather should be presented with available treatment options.[53] The Court of Protection is reluctant to decide hypothetical questions and proceedings are futile if there is no clinician willing to carry out proposed treatment.[54] *Re E* is the only case where continued in-patient treatment was recommended. It is quite possible that the following four cases were precipitated by the *Re E* decision.

The NHS Trust v L and Others [2012][55]

In *The NHS Trust v L*, L had spent around 90% of her life as an inpatient. She was physically frail and in end-stage organ failure. The evidence was that feeding via naso-gastric tube would require sedation and 'the likelihood of death if force-feeding were to be attempted on a chemically sedated basis would run at close to 100%'.[56] A robust case for withdrawal of coercive treatment was made out on the basis that continuing treatment would lead to psychological distress and quite likely result in death.

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[48] Ibid [72], [90].
[49] Ibid [137], per Peter Jackson J.
[50] Ibid, [128].
[51] *A NHS Foundation Trust v Ms X (Official Solicitor)* [2014] EWCOP 35, [56].
[52] *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [135]. See discussion in Richardson G. 2013. Mental capacity in the shadow of suicide: What can the law do? International Journal of Law in Context. 9(1): 87-105.
[53] *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [41].
[54] *AVS v NHS Foundation Trust and B PCT* [2010] EWCA Civ 7.
[55] [2012] EWHC 2741 (COP).
[56] Ibid, [44].

A NHS Foundation Trust v Ms X (Official Solicitor) [2014][57]

X had a slightly better medical prognosis than L. Cobb J recognised that:

> The particular tragedy of the case is that there is a possibility even now that Ms X could live a long and happy life, but that chance is very small indeed – less than 5%. Moreover, I am satisfied that she does not want to die.[58]

X's life expectancy would be normal if she could stop drinking and resume a good diet.[59] However, alcoholism and severe liver disease posed additional risks in relation to any coercive refeeding regime, which resulted in a paradox: '[T]hat if I were to compel treatment, I may (and the doctors argue strongly that I would) be doing no more than facilitating or accelerating the termination of her life.'[60] Some of the risks associated with refeeding flowed from X's likely reaction to it. One possibility was that she would increase alcohol intake, another was that (if denied alcohol) she would attempt suicide.

Re W (medical treatment: anorexia) [2016][61]

In W's case, the objections to refeeding under sedation focussed less on the chances that W would not survive the intervention and more on the ethical dilemmas inherent in a coercive regime:

> The first proposal was for W to be re-fed under sedation. This would involve her being rendered unconscious for up to 6 months and fed by tube until she gained a BMI of 17.5. This proposal has not been pursued, rightly in my view. It is an unprecedented step and there were numerous potential objections about its ethical basis, W's objections, the unavailability of clinicians to carry it out, and the improbability that it would bring about sustainable change.[62]

Recall that the same judge, Peter Jackson J, also presided in the case of E where it was accepted that:

> She would be stabilised and fed with calorific material via a naso-gastric tube or a PEG tube inserted through her stomach wall. Any resistance would be overcome by physical restraint or by chemical sedation. The process would continue for a year or more.[63]

Clearly refeeding under sedation is not itself 'unprecedented'.[64] The key difference between *Re E* and *Re W* for Peter Jackson J, was that for W all available treatment options, in a wide range of treatment settings had been tried to no avail.[65] In E's case, conversely, the evidence was that treatment options were not exhausted. Treatment could not at that point be considered futile.[66]

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[57] [2014] EWHC 35 (COP).

[58] Ibid, [11].

[59] Ibid, [24].

[60] Ibid, [42].

[61] [2016] EWCOP 13.

[62] Ibid, [20].

[63] *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [44].

[64] See Royal College of Psychiatrists. 2014. Management of Really Sick Patients with Anorexia Nervosa' (MARSIPAN) CR198, Appendix 6.

[65] *Re W (medical treatment: anorexia)* [2016] EWCOP 13, [18].

[66] *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [138]. 'I would not overrule her wishes if further treatment was futile, but it is not. Although extremely burdensome to E, there is a possibility that it will succeed.'

Re W concerns clinical futility of a different nature to *The NHS Trust v L* and *A NHS Foundation Trust v X*. It was enough in *Re W* that W's Anorexia Nervosa was severe, unremitting and enduring. These factors indicated that a cure could not be hoped for.[67] *Re W* is thus the closest indication that the court might be amenable to the views that SEAN can potentially be considered terminal, compulsory treatment may be futile, and palliative management may be clinically appropriate.

Cheshire & Wirral Ptnr NHS FT v Z [2016][68]

The risks of harm associated with a coercive refeeding regime were considerable in Z's case, though the evidence that it could lead to death was weaker than in L and X's cases. The court differentiated between physical and chemical restraint, which posed different psychological and physical risks. Because Z had osteoporosis, physical restraint would probably result in musculoskeletal injury.[69] Chemical sedation posed a '"very high risk" of respiratory or cardiac arrest as well as the risk that the sedation option could lead to some other iatrogenic cause of death'.

The next sections outline risks that flow from the potential interpretations of this series of cases. One is that clinicians might rely on the outcome of the cases without due consideration of the nuanced judicial examinations of the individual facts. This could potentially lead to both assumptions of incapacity in cases of SEAN and overreliance on the stated preferences of the patient when considering best interests. In future cases, it is argued that more could be done to protect P's rights, will and preferences.

IV. CAN PATIENTS WITH SEAN HAVE MENTAL CAPACITY?

To understand the potential in practice for patients with SEAN to be assumed to lack capacity, we must first turn to the principles governing the Mental Capacity Act 2005 (MCA). The framework of the legislation has been articulated by Peter Jackson J in *Re E*[70] in the following terms:

> People with capacity are entitled to make decisions for themselves, including about what they will and will not eat, even if their decision brings about their death. The state, here in the form of the Court of Protection, is only entitled to interfere where a person does not have the capacity to decide for herself.
>
> By contrast, where a person lacks capacity, there is a duty to make the decision that is in her best interests.
>
> The first question therefore is whether the person has capacity. The second, which can only arise if she does not, is what decision is in her best interests.

In all five cases, the court found that P lacked capacity. Anorexia Nervosa constitutes an 'impairment of, or disturbance in the functioning of, the mind or brain' so as to satisfy section 2(1) of the Mental Capacity Act test. Section 3(1) sets out the second stage of the two-part test:

> For the purposes of section 2, a person is unable to make a decision for himself if he is unable—

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[67] *Re W (medical treatment: anorexia)* [2016] EWCOP 13, [45].

[68] [2016] EWCOP 56.

[69] Ibid [16].

[70] *Re E (medical treatment: anorexia)* [2012] EWCOP 1639, [7]-[9].

> (a) to understand the information relevant to the decision,
>
> (b) to retain that information,
>
> (c) to use or weigh that information as part of the process of making the decision, or
>
> (d) to communicate his decision (whether by talking, using sign language or any other means).

In assessing P's capacity, the court is interested not only in the patient's understanding but also the ability to use and weigh the information. The MCA Code recognises that section 3(1)(c) concerning the ability to use and weigh information may be particularly pertinent to patients with Anorexia Nervosa.[71] X was found to be unable to use and weigh the information relating to her Anorexia Nervosa, though she retained capacity in relation to her decision to imbibe alcohol.[72] The evidence was that she could understand the information needed to make decisions about alcohol but not about food.

Two concerns about the capacity assessment of patients with Anorexia Nervosa are these: First, there is an assumption of incapacity in the terms of the declaration sought. In *A NHS Foundation Trust v X*, for example, the NHS Trust sought a declaration that it was not in X's best interests to subject P to treatment that may prolong life by compulsorily detaining and treating her against her wishes. This limited the court's scope to assess capacity, not because they could not refute the Trust's conclusion regarding capacity, but because it framed the decision with respect to which capacity is assessed, as one relating to refusal of nutrition. The second concern is articulated by Wang, who argues that the application of the MCA in *A NHS Foundation Trust v X* is incompatible with the UN CRPD.[73] If the decision was characterised as options between choosing a shorter life of better quality and a possibility of full recovery rather than simply as a refusal of refeeding, then P might, depending on their ability to understand, use and weigh these issues, retain capacity. The narrow focus prevented X from judging whether quality or duration of life was more important. The specific decision subject to an assessment of capacity was not necessarily whether to refuse or accept nutrition, but whether to refuse or accept treatment *that X considered futile*.

To focus on the narrow conception of P's refusal of treatment is, we would suggest, at odds with the position taken in the UK Supreme Court decision of *Montgomery,* a leading case on informed consent. The Supreme Court focused on P's entitlement to choose between relevant options[74] 'so that [P] is then in a position to make an informed decision'.[75] In the words of Lady Hale:

> Most decisions about medical care are not simple yes/no answers. There are choices to be made, arguments for and against each of the options to be considered, and sufficient information must be given so that this can be done.[76]

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[71] Office of the Public Guardian. 2013 (updated 2016). MCA Code of Practice, 4.22.

[72] *X NHS Trust v T (adult patient: refusal of medical treatment)* [2004] EWHC 1279 (Fam), [28] –[30].

[73] Wang DWL. 2015. Mental Capacity Act, Anorexia Nervosa and the choice between life-prolonging treatment and palliative care: A NHS Foundation Trust v Ms X. Modern Law Review 78(5); 871-882.

[74] *Montgomery v Lanarkshire Health Board* [2015] UKSC 11, [82], [87], [89] per Lords Reed and Kerr.

[75] Ibid, [90] per Lords Reed and Kerr.

[76] Ibid, [109].

The decision around treatment for SEAN is not simply a matter of saying yes or no to nutrition and neither should the assessment of capacity be confined to this issue.

V. CAN PATIENTS WITH 'SEAN' GIVE CAPACITOUS REASONS FOR REFUSING TREATMENT?

The last section argued that there are circumstances where the 'decision' in relation to which capacity is assessed should be the broader decision about quality and duration of life rather than the narrow issue of nutrition. If so, it might still be argued that the broader decision is strongly influenced by the Anorexia Nervosa, in which case it is important to ascertain in each individual case whether there are sufficient capacitous reasons to support the refusal of treatment.

There is authority for the proposition that a distinction should be drawn between cases where P cannot make a decision and cases where P's views are based, in part, on rational considerations. In *Re SB*[77], a 37-year-old woman with bipolar disorder was detained under section 2 of the MHA. Holman J held that, contrary to expert opinion, P retained capacity to elect the termination of her pregnancy at 23 weeks' gestation. Experts agreed that P understood what a termination entailed but was basing the decision upon 'flawed evidence and paranoid beliefs'.[78] The evidence was that P wanted the baby until the point at which she came off medication (probably to protect the baby) and was beset with paranoid thoughts. Her family considered the decision unwise, but Holman J made clear that, applying section 1(4) of the MCA, an unwise determination cannot be equated with an incapacitous decision. Holman J recognised that the views of experts are usually decisive: 'But those are generally cases in which the patient himself or herself is not positively and strongly asserting, and actually giving evidence, that he or she has the required capacity.'[79] SB was not 'unable to make a decision'. The experts asserted that P could not 'use or weigh' the information or process the consequences of the decision in accordance with section 3(4). But SB gave rational reasons for wanting an abortion that were not related to her paranoia: she did not want to have a child in detention or to have a child just to give it up for adoption.[80]

Can rational reasons be given for refusing treatment for Anorexia Nervosa? Ambivalence is a feature of Anorexia Nervosa, with patients typically valuing the disorder and wishing to keep it, despite suffering and evidence of harm if they do not accept treatment.[81] Furthermore, a challenge with severe Anorexia Nervosa is that patients are typically articulate, yet may have difficulties in separating an authentic self as opposed to a self which is inextricably entwined with the values, wishes and desires of Anorexia Nervosa. The attachment to Anorexia Nervosa can be so strong that patients may prefer to die than to gain weight, or value the disorder more than life itself. As a result, it is important to examine carefully what motivations and reasoning underpin P's expressed wish to live or to die. Thus, the question of whether P's will to die flows from a sense of hopelessness and a desire to end the struggle or alternatively

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[77] *Re SB (a patient) (capacity to consent to termination)* [2013] EWHC 1417 (COP).

[78] Ibid, [34].

[79] Ibid, [36].

[80] Ibid, [41]-[42].

[81] Hope T, Tan J, Stewart A, McMillan J. 2013. Agency, ambivalence and authenticity: the many ways in which anorexia nervosa can affect autonomy. International Journal of Law in Context 9(1): 20-36.

from an articulated preference to die rather than gain weight, is relevant when considering P's ability to use and weigh information.

There are parallels between *Re SB* and X, who also 'made a decision'. Whilst X's perception of her body image and weight were irrational, it is arguable that she also gave rational reasons for wanting to avoid further compulsion: X set out her views in writing, stating that the therapy was making her worse and: 'Whatever time I have left I just want to live each day alongside my granddad and [siblings], who are my world.'[82] In a recent (as yet unreported) U.S. case, the Morristown County Superior Court in New Jersey (a state court with state-wide trial and appellate jurisdiction) ruled that a 29-year-old woman with SEAN referred to as Ashley G (AG), could not be treated against her capacitous decision to refuse food.[83] According to media reports, AG had previously been treated against her will and suffered heart failure because of refeeding syndrome.[84] Her Guardian argued that palliative care was appropriate and AG's parents agreed. Tube-feeding would likely result in musculoskeletal injury due to osteoporosis. The Department of Human Services and its Division of Mental Health and Addiction Services opposed the request but did not appeal the court's decision. As in X's case, AG understood that non-treatment could result in her death. Judge Paul Armstrong stated that her testimony was 'forthright, responsive, knowing, intelligent, voluntary, steadfast and credible'.[85] AG retained capacity and, in accordance with her wishes, she was transferred to a palliative care unit where she died.[86]

Based on these five decisions from England and Wales, it is difficult to conceive of a case where someone with SEAN would be considered capacitous in relation to decisions to refuse food. Peter Jackson J recognised that E was in a Catch 22 situation: 'By deciding not to eat, she proves that she lacks capacity to decide at all.'[87] It seems that, by focusing the question on P's ability to make decisions about nutrition, we stray very close to a presumption of incapacity. We would respectfully recommend that in future cases, a patient-centred position is used to frame the decision which is subject to a capacity assessment. Even if the patient cannot make a capacitous decision about nutrition, they may be able to provide rational reasons for refusing treatment for Anorexia Nervosa. In such cases, clinicians or the court might accept that the patient can make a capacitous decision to do so.

VI. PARALLELS WITH ASSISTED DYING

As a brief but relevant aside, it is worth noting that questions surrounding the authenticity of treatment decisions made by those with mental disorder are not limited to Anorexia Nervosa. There are parallels with debates around assisted dying. Internationally, there is evidence of mounting acceptance of the right to assisted

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[82] *X NHS Trust v T (adult patient: refusal of medical treatment)* [2004] EWHC 1279 (Fam), [51].

[83] Schmidt S. 2016. Anorexic woman weighing 69 pounds has a right to starve, court rules. Washington Post. 22 November: See https://www.washingtonpost.com/news/morning-mix/wp/2016/11/22/anorexic-woman-weighing-69-pounds-has-a-right-to-starve-court-rules/?utm_term=.08d50a6ef4ca.

[84] Ibid.

[85] King K. 2016. Anorexic can refuse force-feedings, court rules. Wall Street Journal. 21 November. See https://www.wsj.com/articles/anorexic-can-refuse-force-feedings-court-rules-1479777914.

[86] Wright P. 2017. Anorexic, bulimic woman who fought force-feeding dies at 30. Associated Press. 22 February. See http://news.findlaw.com/apnews/804b0c4fb3bd4fa4b7cd07b832d8cebf.

[87] *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [53].

suicide.[88] In countries where assisted dying is lawful, it is often limited to terminal illness and sometimes also to non-terminal but presently incurable degenerative conditions, such as motor neuron disease. Conversely both the Netherlands and Belgium have recognised that, in principle, patients with non-somatic illness, such as clinical depression, are eligible for assisted dying. There are recent reports of a 20-year-old woman with Anorexia Nervosa accessing assisted dying in the Netherlands,[89] and of UK patients with dementia dying at the Dignitas facility in Zurich.[90] Schuklenk and van der Vathorst have argued that competent patients who suffer from depressive disorders that are treatment-resistant are discriminated against if they are excluded from the assistance in dying offered to other groups.[91] The battle to ascertain and uphold the will of patients with mental disorder is one fought on a number of fronts.

VII. HOW FAR ARE P'S VIEWS RELEVANT TO AN ASSESSMENT OF BEST INTERESTS?

Given that the courts ruled that E, L, X, W and Z *lacked* capacity, the decisions turned on an assessment of their best interests. This section sets out the applicable test and considers the relevance of P's views. In the cases of L, X, W and Z, the judicial decisions coincided with each patient's stated wishes. It is difficult to discern from the cases how far this flowed from an attempt to comply with their will and preferences. This section affirms the importance of doing so, but also sounds notes of caution due to the difficulties of discerning will and preferences in cases of Anorexia Nervosa and the dangers of conflating the two.

Best interests cannot be defined by a single test.[92] A balance sheet approach is often used as an 'aide-mémoire'[93] to assist in the weighing of medical and non-medical factors set out in section 4 of the MCA.[94] In *Aintree*, Lady Hale recognised the common law presumption that it is in P's best interests to stay alive.[95] Whilst there are no general principles applicable to when the presumption might be rebutted, there has been support for a 'touchstone of intolerability'[96] assessed by a balancing exercise.

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[88] See, for example, *Carter v Canada (Attorney General)*, 2015 SCC 5, [2015] 1 SCR 331. Also Span P. 2017. Physician aid in dying gains acceptance in the UK. The New York Times. 16 January: reporting new assisted dying legislation in California (June 2016); Colorado (November 2016); Columbia (December 2016). See also dissenting judgments of Lady Hale and Lord Kerr in *R (Nicklinson) v Ministry of Justice; R (on the application of AM) v The Director of Public Prosecutions* [2014] UKSC 38.

[89] Doughty S. 2016. Sex abuse victim in her 20s allowed to choose euthanasia in Holland after doctors decided her post-traumatic stress and other conditions were incurable. Daily Mail. 10 May. See http://www.dailymail.co.uk/news/article-3583783/Sex-abuse-victim-20s-allowed-choose-euthanasia-Holland-doctors-decided-post-traumatic-stress-conditions-uncurable.html.

[90] Bodkin H. 2017. Struck-off psychiatrist helped six Britons to die in Swiss suicide clinics. The Telegraph. 22 January. See http://www.telegraph.co.uk/news/2017/01/22/struck-off-psychiatrist-helped-six-britons-die-swiss-suicide/.

[91] Schuklenk U, Vathorst SVD. 2015. Treatment-resistant major depressive disorder and assisted dying. Journal of Medical Ethics 41; 577-583.

[92] *R (Burke) v GMC (Official Solicitor intervening)* [2005] EWCA Civ 1003, [63] per Lord Phillips.

[93] *Re F (A Child) (International Relocation Cases)* [2015] EWCA Civ 882, [52] per McFarlane LJ warning that the balance sheet approach must be used as 'a route to judgment and not a substitution for the judgment itself'.

[94] *Re A (male sterilisation)* [2000] 1 FLR 549, 560 F-H per Thorpe LJ; *W v M and Ors* [2011] 1 WLR 1653, [222] per Baker J.

[95] *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [35].

[96] Ibid, [37].

That exercise requires the decision-maker to consider 'welfare in the widest sense, not just medical but social and psychological'.[97] This requires consideration of:

> The nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.[98]

Lady Hale was clear that whilst the test is objective: 'The purpose of the best interests test is to consider matters from the patient's point of view'.[99] Where P cannot make a capacitous decision, then it is necessary to make an assessment of P's values and beliefs, wishes and feelings in order to make 'the choice which is right for him as an individual human being'.[100]

This position brings the law closer to compliance with the UN CRPD. Article 12(4) views respect for P's rights, will and preferences, as an integral part of equal recognition before the law. In 2017, the Law Commission recommended that P's wishes and feelings should be ascertained and given weight[101] and departed from only if necessary and proportionate.[102]

In the five cases, P's wishes are central to the analysis of best interests and in each case, P consistently and articulately stated a wish to avoid compulsory refeeding. In *Re E* Peter Jackson J said:

> I agree … that particular respect is due to the wishes and feelings of someone who, although lacking capacity, is as fully and articulately engaged as E.[103]

In Z's case, voluntary treatment was said to have the best hope of preserving Z's autonomy.[104] In each judgment, credence was afforded to P's views and in principle this is to be celebrated. In *Briggs v Briggs*, Charles J said:

> if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in favour of preserving life.[105]

However, Charles J also recognised that the best interests determination is fact sensitive and exceptions may apply, for example, where P has previously made harmful decisions which the court would be reluctant to make on P's behalf; where P's current expression of their wishes (such as a desire to leave hospital) fails to factor in or weigh competing factors; and where clinical conditions and their effect impact on P's decision-making.[106] These factors are highly relevant to the SEAN cases. Anorexia Nervosa can undermine autonomy in several ways,[107] and though 'will' and

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[97] Ibid, [39].
[98] Ibid, [39].
[99] Ibid, [45].
[100] Ibid, [45].
[101] Law Commission. 2017. Mental Capacity and Deprivation of Liberty. Law Com No 372, 14.7.
[102] Ibid 14.16–14.18 and rec 40; Draft Bill, cl 8(2) and (3).
[103] *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [127] and see [132].
[104] *Cheshire & Wirral Ptnr NHS FT v Z* [2016] EWCOP 56, [19] per Hayden J.
[105] *Briggs v Briggs* [2016] EWCOP 53, [62].
[106] Ibid, [60].
[107] Hope T, Tan J, Stewart A, McMillan J. 2013. Agency, ambivalence and authenticity: the many ways in which anorexia nervosa can affect autonomy. International Journal of Law in Context 9(1): 20-36.

'preferences' are often conflated,[108] the SEAN cases serve as a powerful illustration of how the two might clash. There may, for example, be a stated preference (not to eat) that conflicts with an authentic will (to live); a current preference contradictory to a past preference; or the Anorexia Nervosa might itself influence or generate a willingness to die (though not usually a wish to die) that flows from the desire to be thin, in which case P's 'rights' may conflict with both P's will and preferences.

Coggon persuasively argues that, where possible, the same weight should be given to P's wishes and feelings when P lacks capacity as when P retains it.[109] The MCA requires by section 4(6) that consideration is given, as far as is reasonably ascertainable,[110] to P's past and present wishes and feelings, beliefs and values. As Coggon acknowledges, difficulties arise where P has expressed conflicting views. Does a past capacitous view take precedence over a current incapacitous view? Section 4 of the MCA gives little guidance as to how to deal with conflict between past and present wishes. In SEAN cases, it may not be clear whether P ever possessed the relevant insight into their condition such that P could make a capacitous decision about nutrition. There was some acknowledgment of this in Z's case: Having considered the 'broader canvass' of Z's life,[111] Hayden J concluded: 'Sadly, in this case that has proved to be a very short exercise. Z's world, since she was 15 years of age, has been entirely circumscribed by her eating disorder.'[112]

Analysing *Cheshire & Wirral Ptnr NHS FT v Z*, Clough convincingly demonstrates that consideration of will and preferences must go beyond a mere consideration of the issue of nutrition.[113] As we have seen, all five patients wanted to avoid a coercive regime, but whilst E and X wanted to be allowed to die with dignity[114] L, W and Z expressed a hope and desire to live. L felt that if funding were secured to enable her to move to a nursing home, she would survive.[115] W wanted to return to education and pursue a career.[116] Z believed that, if allowed to return home, she would survive.[117] Given the conflicting nature of the desire to live and the desire to avoid compulsory refeeding, it is unclear in L, W and Z's cases which should take priority.

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[108] Committee on the Rights of Persons with Disabilities. 2014. General Comment No 1: Article 12 Equal Recognition Before the Law. CRPD/C/GC/1. See discussion in Skowron P. 2015. Will, preferences, and the danger of confusing wants and needs – some thoughts on the UNCRPD. University of Manchester School of Law Blog. See http://blog.law.manchester.ac.uk/will-preferences-and-the-danger-of-confusing-wants-and-needs-some-thoughts-on-the-uncrpd/.

[109] Coggon J. 2016. Mental capacity law, autonomy, and best interests: An argument for conceptual and practical clarity in the Court of Protection. Medical Law Review 24(3): 396-414. And consider *Winspear v City Hospitals Sunderland NHS Foundation Trust* [2015] EWHC 3250 (QB), where Blake J found that the duty to consult before issuing a DNACPR notice applied equally in respect of patients with and without capacity.

[110] See reform proposals: Law Commission. 2017. Mental capacity and deprivation of liberty. Law Com No 372, 14.16–14.18 and rec 40; Draft Bill, cl 8(2) and (3).

[111] As per *Re S (adult patient: sterilisation)* [2001] (Fam) 15; *County Durham & Darlington NHS Foundation Trust v SS* [2016] EWHC 535 (Fam).

[112] *Cheshire & Wirral Ptnr NHS FT v Z* [2016] EWCOP 56, [13].

[113] Clough B. 2016. Anorexia, capacity, and best interests: Developments in the Court of Protection since the Mental Capacity Act 2005. Medical Law Review 24 (3): 434-445.

[114] *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [76]. *A NHS Foundation Trust v Ms X (Official Solicitor)* [2014] EWCOP 35, [50].

[115] *The NHS Trust v L and Others* [2012] EWHC 2741 (COP), [31].

[116] *Re W (medical treatment: anorexia)* [2016] EWCOP 13, [28].

[117] *Cheshire & Wirral Ptnr NHS FT v Z* [2016] EWCOP 56, [14].

Just as we have argued that the capacity assessment should look beyond the narrow issue of nutrition, so too, where P lacks capacity, the best interests assessment should extend beyond that narrow focus. The danger inherent in the five cases is twofold. Firstly, it is not clear that a sufficiently nuanced consideration of best interests was undertaken. Secondly, it is possible that the cases may be misconstrued in practice and that patients shown (or assumed) to lack capacity will nonetheless be given the choice to refuse treatment. Unless a suitably nuanced consideration of will and preferences is undertaken, there is potential in clinical practice to assume that the stated preferences of the patient represent their best interests where, in some cases, in-patient treatment might still be appropriate and potentially efficacious.

VIII. TREATMENT UTILITY AND FUTILITY

In England and Wales, the issue of treatment efficacy - that is, how effective a proposed treatment is likely to be in the opinion of the clinician - influences clinicians' choices between two different but overlapping legal regimes: The Mental Capacity Act 2005 and the Mental Health Act 1983. We have shown that there is much debate as to the efficacy of treatment in cases of SEAN and this section explores the impact of that uncertainty.

Mental Health Act

As we have seen, in-patient treatment under the MHA 1983 does not necessarily require patient consent. A minimum requirement is that the treatment does not violate Article 3 of the ECHR, which prohibits inhuman or degrading treatment. Compulsory treatment violates Article 3 unless shown to be in P's best interests on the basis that a 'medical necessity has been convincingly shown to exist'.[118] In *R (N) v (M)* the test for necessity was said to include:

> (a) how certain is it that the patient does suffer from a treatable mental disorder; (b) how serious a disorder is it; (c) how serious a risk is presented to others; (d) how likely is it that, if the patient does suffer from such a disorder, the proposed treatment will alleviate the condition; (e) how much alleviation is there likely to be; (f) how likely is it that the treatment will have adverse consequences for the patient; and (g) how severe may they be.[119]

Where the treatment decision is made by clinicians under the MHA framework, the first factor listed in *R (N) v (M)* is affected by a revision of the MHA in 2007, which replaced the requirement of treatability with one of 'appropriate' treatment.[120] This affords clinicians significant discretion. How the discretion is exercised will depend, in part, on the clinician's position on whether the particular case of Anorexia Nervosa can and should be classified as 'severe and enduring' and the effect they believe this has on treatment efficacy. Clinicians who consider the disorder to be a chronic condition might see value in continued treatment. The MHA Code of Practice recognises that for some patients, management rather than cure is 'all that can be hoped for'.[121] In common with many mental health disorders, eating disorders cannot always be cured

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[118] *Herczegfalvy v Austria* [1993] 15 EHRR 437, 484; *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [126].

[119] [2002] EWCA Civ 1789, [19] per Dyson LJ.

[120] Mental Health Act 1983 s 58(3)(b), as amended by the MHA 2007. See Bartlett P. 2011. Standards for compulsory treatment for mental disorder under the Mental Health Act 1983. Medical Law Review 19(4): 514-547.

[121] Department of Health. 2015. Mental Health Act 1983 Code of Practice. TSO, paras 6.15-6.16.

and a diagnosis may be life-long. In these cases, treatment under the MHA might continue. On the other hand, some, who accept that a case is severe and enduring, will also accept that compulsory treatment is no longer efficacious, in which case it may no longer be apposite to treat under the MHA. Media reports of the U.S. case of AG, discussed above, go so far as to classify that case of Anorexia Nervosa as a 'late terminal' condition.

Mental Capacity Act: Cure or management?

If treatment is no longer considered appropriate under the MHA, the MCA regime remains relevant. In *Briggs*, Charles J recognised that P's views might not be followed if P wants something that 'is not an available option'.[122] In the five SEAN cases, P was not requesting, but refusing, treatment. Still, the perceived utility or futility of the treatment options is pertinent: A refusal of something that would not be offered needs little by way of justification. The right to life enshrined in Article 2 of the European Convention on Human Rights is not absolute[123] and the best interests test goes wider than medical necessity[124] to encompass the value of treatment.[125] In *Aintree*, Lady Hale made it clear that futility must be assessed against the wide interests of the patient; treatment is not futile if it brings benefit to the patient, even if it does not improve the underlying medical condition.[126]

Unfortunately, the cases evince dicta suggestive of a more limited view of the purpose of treatment. When combined with a narrow focus on P's expressed views, the judgments form a powerful incentive for clinicians to release objecting SEAN patients from in-patient treatment programmes. The dicta in question focus on cure as the purpose of treatment. In W's case, it was said that interventions had for some time merely kept her alive rather than addressed the underlying condition.[127] To keep P on the unit or move P to another unit was considered cruel given the restrictions it would involve and the remoteness of any prospects for change.[128] In X's case, too, it was established that the purpose of refeeding was not simply to avert the risk of death, but rather to treat the underlying conditions. The purpose was for X:

> i) to gain weight,
>
> ii) more importantly to gain insight into the benefits of psychotherapeutic interventions to address the causes of her illnesses, and then
>
> iii) yet more crucially still, to avail herself of those psychotherapeutic interventions.[129]

The conclusion in X's case was that: 'Any refeeding treatment would not now, as it never has, address the cause of the Anorexia Nervosa; it would merely serve to prolong life'.[130] In Z's case, the judge concluded that discharge from the MHA

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[122] *Briggs v Briggs* [2016] EWCOP 53, [60].

[123] *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [120] and *The NHS Trust v L and Others* [2012] EWHC 2741 (COP), [18] citing *Airedale NHS Trust v Bland* [1993] AC 789.

[124] *Re S (sterilisation: patient's best interests)* [2000] 2 FLR 389.

[125] Office of the Public Guardian. 2013 (updated 2016). MCA Code of Practice, 5.31.

[126] *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [40], [44] per Lady Hale.

[127] *Re W (medical treatment: anorexia)* [2016] EWCOP 13, [38].

[128] Ibid [40].

[129] *A NHS Foundation Trust v Ms X (Official Solicitor)* [2014] EWCOP 35, [41] per Cobb J.

[130] Ibid [43].

framework and treatment on a voluntary basis 'is ultimately the only proposal which carries any vestige of hope and most effectively preserves Z's dignity and autonomy'.[131]

Coggon argues that the concept of the treatment decision needs further evaluation.[132] The narrow view of the purpose of treatment is potentially at odds with Lady Hale's assertion in *Aintree* that: '[I]t is setting the goal too high to say that treatment is futile unless it has 'a real prospect of curing or at least palliating the life-threatening disease or illness from which the patient is suffering'.[133]

We have suggested above that the decision against which capacity is assessed should encompass P's decision surrounding the value of further treatment. We would further argue that this approach should extend to best interests assessments so as to take account of whether a short- or long-term view of the purpose of treatment is *relevant* to P. A short-term view may be relevant in cases where the prognosis is poor but prolonged life coincides with the patient's will or values.[134] It might also be relevant to a SEAN case if there is evidence that refeeding could enhance capacity (by reducing the adverse effects of physical frailty or sedative drugs); or that refeeding might lead to a more positive engagement with services, family or education, even if the evidence suggests that P might later relapse. The closer we come to assessing futility of treatment options against the goal of complete cure, the easier it will be to demonstrate. This may be failing P if it coincides with their stated preference but not their will or values and their desire to live.

IX. CONCLUSION

The judges in the decisions of E, L, X, W, and Z carefully and compassionately considered the patients' wishes. In four of the cases they granted the declarations sought by the NHS Trusts to cease compulsory treatment in compliance with the wishes of each P, with the support of their families and clinicians.

This paper has focussed on the human rights implications of the judgments in law and clinical practice. It is important to acknowledge that the judges operated under several constraints. Firstly, they were limited by the options put to them by the clinical team. There is no general power to decide how clinicians should treat a patient.[135] Secondly, the courts were powerless to affect the timing of the decisions. NHS Trusts are advised to bring a claim only once a structured assessment has taken place,[136] but by the time the cases of E, L, X, W and Z came to court, the condition of each of the patients was dire.[137] Finally, the question of resources is an ever-present undercurrent.[138] NICE has

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[131] *Cheshire & Wirral Ptnr NHS FT v Z* [2016] EWCOP 56, [19] per Hayden J.

[132] Coggon J. 2015. Alcohol dependence and anorexia nervosa: Individual autonomy and the jurisdiction of the Court of Protection: An NHS Foundation Trust v Ms X [2014] EWCOP 35. Medical Law Review 23; 659-67.

[133] *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [43].

[134] See for example *St George's Healthcare NHS Trust v P&Q* [2015] EWCOP 42.

[135] *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [18] per Lady Hale.

[136] *St George's Healthcare NHS Trust v P&Q* [2015] EWCOP 42.

[137] See *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [40]. And on importance of timing of application more generally, see *Sandwell and West Birmingham Hospitals NHS Trust v CD* [2014] EWCOP 23.

[138] But see *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [143]: 'I record that the state, having instigated this plan of action for E in the way that it has, is now honour bound to see it through

acknowledged that 'eating disorders, in particular Anorexia Nervosa, result in substantial economic burdens upon healthcare resources'.[139] Clinicians must consider the resource implications of on-going treatment, just as treatment availability or lack thereof[140] may have paradoxically contributed to the severe and enduring nature of the condition now suffered by the patient.

Operating within these constraints, it may yet be possible in future cases to subject a clinical view that P lacks capacity to greater scrutiny. This would allow judges to enhance protection of P's autonomy rights and to provide valuable practical guidance for clinicians. We have made three principal recommendations that aim to put the rights, will and preferences of P at the heart of decision-making:

(1) The court should resist appointing the same expert in all cases. In a clinical setting, a plurality of views exists on the staging and classification of Anorexia Nervosa, prognosis of patients with SEAN, their capacity, the choice between Mental Capacity Act or Mental Health Act regimes, and ultimately their best interests. Understood as a potentially *terminal* condition, the focus might be on when to stop treatment and focus on palliative management. Understood as a *treatable* or indeed *chronic* condition, the focus will be on refusal of refeeding in which case, even if capacitous, P's refusal might be overruled under the MHA framework on the basis that appropriate treatment and prospect of recovery or continued life with reasonable quality exists.

(2) A patient-centred assessment of capacity will flexibly interpret the decision about which capacity is assessed by reference to the patient's views on the value of treatment. A patient who lacks capacity to make a decision about nutrition may have capacity to determine that treatment is no longer worthwhile.

(3) Where it is found that P lacks capacity, and the Court of Protection is asked to determine best interests, the Court should seek to identify P's views, contrasting current and past views; rights, will and preferences. Exclusive focus on P's expressed views on refeeding risks reliance on stated preferences that can potentially clash with P's will (as, for example when P refuses food but desires to live). This is particularly troublesome when P's (unauthentic) views of futility coincide with a clinical view that treatment of SEAN has become futile, or with a judicial assessment of the appropriateness of treatment against the goal of cure rather than management of the disorder. Where P expresses views about the value and purpose of treatment, these views are relevant to the best interests assessment. Where they constitute an authentic expression of P's will, they will guide clinicians and the court in determining best interests from P's point of view.[141]

Though the judgments do not promote such a broad-brush approach, a focus on the outcomes of the five cases in combination might lead to an assumption, in clinical practice, that P cannot make a capacitous decision in relation to the treatment of SEAN, and, where a lengthy programme of intervention has not addressed the

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by the provision of resources in the short, medium and long term. Had the authorities not made that commitment, I would not have reached the conclusion that I have.'

[139] NICE. Draft: Eating Disorders - Recognition and Treatment. [GID-CGWAVE0703], p 35.

[140] NHS Confederation, Mental Health Network. 2016. Funding for Mental Health. 15 June: Reports a £600m real-term fall in NHS mental health funding over the course of the last parliament. See http://www.nhsconfed.org/resources/2016/06/funding-for-mental-health

[141] *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [45].

underlying condition, that further compulsory treatment might be considered futile. This can and should be avoided. Palliative management should be based on need rather than diagnosis; capacity should be decision- and not disease-specific.

ANALYSING THE DEFINITION OF DISABILITY IN THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES: IS IT REALLY BASED ON A 'SOCIAL MODEL' APPROACH?

KATERINA KAZOU*

ABSTRACT

This article challenges the generally accepted view that the UN Convention on the Rights of Persons with Disabilities 2006 (CRPD) is based on the 'social model of disability'. The 'social model' understands disability as a social situation, and particularly a form of social oppression imposed on people with impairments, which is caused by social and environmental barriers that exclude them from participating in society and which is entirely distinguished from their individual impairment. The article argues that the definition of disability in the CRPD is closer to the definition provided in WHO's International Classification of Functioning, Disability and Health (ICF). The ICF understands disability as the multi-dimensional and interactive experience of a wide range of difficulties in functioning; in particular, these difficulties include impairments, limitations in performing activities and restrictions in participating in life situations, and arise out of the complex interaction between health conditions, personal factors and barriers in the physical and social environment. Associating the CRPD with the ICF rather than the 'social model' might have positive implications for its implementation, as it can avoid the criticism faced by the 'social model' for its limitations, especially for considering impairment as being entirely irrelevant to the experience of disability, and therefore governments and policy makers might be less sceptical towards the CRPD and more willing to engage with it. At the same time, the valuable insights of the 'social model' regarding the disabling effect of social and environmental barriers can be retained, as the ICF recognises this too, but without ignoring the relevance of impairment to the experience of disability or minimising the health needs of persons with disabilities.

I. INTRODUCTION

The UN Convention on the Rights of Persons with Disabilities (CRPD)[1] is one of the nine core international human rights treaties and, as of July 2017, 160 States have signed it and 174 have ratified it.[2] It is the first legally binding instrument on the issue of disability[3] and its purpose is to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with

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[1] United Nations Convention on the Rights of Persons with Disabilities (CRPD), adopted by the General Assembly on 13 December 2006, UN Doc. A/RES/61/106, 24 January 2007 (entered into force 3 May 2008).

[2] See the UN Enable website: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> accessed 31 July 2017.

[3] Previous international 'soft law' instruments on the issue of disability include the *Declaration on the Rights of Mentally Retarded Persons 1971*, the *Declaration on the Rights of Disabled Persons 1975*, the *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health 1991* and the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities 1993*.

disabilities, and to promote respect for their inherent dignity'.[4] The CRPD applies to all persons with disabilities, including those with mental,[5] or psychosocial,[6] disabilities.[7]

This article considers the definition of disability set out in the CRPD, and disputes the generally accepted view[8] that this is based on the 'social model of disability'. This term refers to the best known social approach to disability, developed in Britain during the 1970s and 1980s by disabled people themselves. The British 'social model' approach understands disability as a socially created problem, caused by social and environmental barriers that exclude people with impairments from participating in society, and which is entirely distinguished from their individual impairment.

The article begins with an examination in Part II of the British 'social model' approach to disability, and Part III examines the definition of disability provided in WHO's International Classification of Functioning, Disability and Health (ICF).[9] The ICF describes disability as the multi-dimensional and interactive experience of a wide range of difficulties in functioning; in particular, these difficulties include impairments, limitations in performing activities and restrictions in participating in life situations, and arise out of the complex interaction between health conditions, personal factors and barriers in the physical and social environment. In light of this, Part IV considers the CRPD definition of disability in its Preamble:

> [D]isability is an evolving concept and … results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.[10]

It is argued that the CRPD defines disability in a way which is closer to the ICF conceptualisation, rather than adopting the British 'social model' approach. Although the connection between the CRPD and the ICF has been noted before,[11] this article provides in addition a full explanation and analysis of this connection, also in contrast to the British 'social model' approach.

II. THE BRITISH 'SOCIAL MODEL' OF DISABILITY

The purpose of this Part is to identify what is meant by, and how disability is understood under, the 'social model', in order to determine in Part IV whether the CRPD defines disability in accordance with this approach. Although still evolving, the unique features that characterise the 'social model of disability' are found in a

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[4] CRPD, Art 1.

[5] The term used in the CRPD, taken to refer to the experience of mental health difficulties.

[6] The term preferred by some, especially - but not only - service users, over 'mental disabilities': see for example World Network of Users and Survivors of Psychiatry, 'Psychosocial Disability' <http://www.wnusp.net/index.php/crpd.html> accessed 31 July 2017; World Network of Users and Survivors of Psychiatry, 'Implementation Manual for the United Nations Convention on the Rights of Persons with Disabilities' (2008) 9 <http://www.wnusp.net/documents/WNUSP_CRPD_Manual.pdf> accessed 31 July 2017.

[7] CRPD, Art 1.

[8] For examples, see below pp 39-40.

[9] World Health Organisation (WHO), *International Classification of Functioning, Disability and Health (ICF)*, endorsed in May 2001, Res. WHA 54.21 of the 54th World Health Assembly (WHO 2001).

[10] CRPD, Pmbl, para (e).

[11] See below p 37.

document called 'Fundamental Principles of Disability',[12] published by the Union of the Physically Impaired against Segregation (UPIAS), and the work of Michael Oliver.[13] Therefore, focus will be placed on how disability is described in the UPIAS document, and Oliver's conceptualisation of the 'social model'.

As stated above, the term 'social model of disability' refers to the British social approach to disability. The various social approaches that have been developed reject the idea that disability is simply a medical problem arising from individual impairment, and draw attention to environment's and society's role in creating disability. The British approach in particular, as will be seen below, denies any causal link between impairment and disability and suggests instead that disability is created solely within society.

Prior to the late 1960s and 1970s, disability, viewed from a medical perspective, was regarded as the result of individual impairment which requires medical care, rehabilitation and individual adjustment. During that period, however, a social approach to understanding the nature and consequences of disability emerged, as disabled activists and organisations controlled and run by disabled people drew attention to their social and economic exclusion and began campaigning for social changes to improve their lives. The previously dominant medical and individual understandings of disability were challenged, and focus was placed instead on the impact of social and environmental barriers and the discrimination and disadvantage experienced by people with impairments.

The social approach was further developed, as disabled people's political activism led to a growing interest in the issue of disability within the academy, especially within sociology. Although disability was traditionally studied within the sub-field of medical sociology, and particularly the sociology of chronic illness and disability,[14] the new discipline 'disability studies' that was developed in the 1980s and 1990s began approaching disability from a social perspective.[15]

The best known social approach has been developed in Britain and is known as the 'social model of disability'; however, social understandings of disability have been advanced by disabled activists and disability studies scholars in several countries. As Tom Shakespeare states in *Disability Rights and Wrongs,* there is a 'family of social-contextual approaches to disability',[16] including, besides the British approach, the

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[12] The Union of the Physically Impaired Against Segregation and the Disability Alliance, *Fundamental Principles of Disability: Being a Summary of the Discussion Held on 22nd November, 1975 and Containing Commentaries from Each Organisation* (UPIAS 1976) <http://disability-studies.leeds.ac.uk/files/library/UPIAS-fundamental-principles.pdf> accessed 31 July 2017.

[13] Michael Oliver, *The Politics of Disablement* (Macmillan 1990); Michael Oliver, *Understanding Disability: From Theory to Practice* (Palgrave 1996).

[14] For a review of the sociological approaches to chronic illness and disability, see Colin Barnes and Geof Mercer, *Exploring Disability* (2nd edn, Polity Press 2010) 43-70.

[15] Note that, although referred to above as 'discipline', disability studies are best described as interdisciplinary. On the development of disability studies, see Colin Barnes, Mike Oliver and Len Barton, 'Introduction' in Colin Barnes, Mike Oliver and Len Barton (eds), *Disability Studies Today* (Polity Press 2002) 1-15; Rannveig Traustadóttir, 'Disability Studies, the Social Model and Legal Developments' in Oddný Arnardóttir and Gerard Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff Publishers 2009) 4-7.

[16] Tom Shakespeare, *Disability Rights and Wrongs* (Routledge 2006) 9.

Nordic 'relational' understanding and the North America 'minority group' approach.[17] Nonetheless, since the British 'social model' approach has been the most influential, this term is often associated with the many social understandings of disability. This however can be misleading because, despite sharing many similarities, the various social approaches also have unique characteristics. What distinguishes the British 'social model' is the radical idea that the cause of disability is found exclusively within society, whereas the role of impairment in creating disability is entirely denied.

This strong view is only adopted by the British 'social model', and it is therefore important to emphasise that it is only the British approach that makes the distinction between impairment and disability; thus, a social approach to disability does not necessarily rely on that distinction.

Union of the Physically Impaired against Segregation (UPIAS)

The British social approach was developed by disabled activists such as Vic Finkelstein[18] and disability studies scholars such as Michael Oliver[19] and Colin Barnes,[20] based on a materialist understanding of disability.[21] The term and conceptualisation of the 'social model of disability' was conceived by Oliver in 1981; however, the basic ideas of this new understanding, most importantly as regards the cause of disability, were introduced in 1976, in UPIAS's 'Fundamental Principles of Disability'. UPIAS was a disabled people's organisation, created in the 1970s, and among its leaders were Paul Hunt and Vic Finkelstein. Disability is described in the document as follows:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability', of people with such impairment. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus

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[17] The 'relational' approach understands disability as a relationship between the individual and the environment, whereas the 'minority group' approach focuses on the discrimination against persons with disabilities and regards civil rights legislation as the appropriate response: See generally Shakespeare, *Disability Rights and Wrongs* (n 16) 23-26. On the 'relational' approach see more specifically Jan Tøssebro and Anna Kittelsaa (eds), *Exploring the Living Conditions of Disabled People* (Studentlitteratur 2004). On the 'minority group' approach see more specifically Harlan Hahn, 'The Politics of Physical Differences: Disability and Discrimination' (1988) 44 Journal of Social Issues 39; Harlan Hahn, 'Antidiscrimination Laws and Social Research on Disability: The Minority Group Perspective' (1996) 14 Behavioral Sciences and the Law 41.

[18] Victor Finkelstein, *Attitudes and Disabled People: Issues for Discussion* (World Rehabilitation Fund 1980).

[19] Oliver, *The Politics of Disablement* (n 13); Oliver, *Understanding Disability: From Theory to Practice* (n 13).

[20] Colin Barnes, *Disabled People in Britain and Discrimination: A Case for Anti-Discrimination Legislation* (Hurst & Company 1991).

[21] According to this understanding, disability is linked to the rise of capitalism and particularly the capitalist mode of production: For an overview of materialist accounts of disability, see Colin Barnes, Geof Mercer and Tom Shakespeare, *Exploring Disability: A Sociological Introduction* (Polity Press 1999) 83-86. See also Brendan Gleeson, 'Disability Studies: A Historical Materialist View' (1997) 12 Disability & Society 179; Mark Priestley, 'Constructions and Creations: Idealism, Materialism and Disability Theory' (1998) 13 Disability & Society 75.

> excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression.[22]

As evident in the above statement, UPIAS adopts a new understanding of disability, which has two main characteristics. First, a distinction is made between impairment and disability, which has been crucial to the British 'social model' of disability. It can be said in particular that this distinction is relied upon to argue that disability is not a problem of functional limitations, but one of social and economic structures. Second, disability is viewed as social oppression, which points to the relationship between those with impairments and the rest of society. These characteristics will now be examined, starting with the way in which impairment and disability are separated in the UPIAS document.

As a starting point, it can be argued that there are two different ways of distinguishing between impairment and disability. First, it might be in terms of their different meaning. By including in the document definitions of impairment and disability, UPIAS highlights that these terms are not synonymous: Impairment is defined as 'lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body', whereas disability is defined as 'disadvantage or restriction of activity'.[23] It is therefore clear that impairment refers to a problem with the body, whereas disability refers to something else, namely a difficulty in performing activities.

UPIAS however goes further than that; besides separating impairment from disability in the sense that they do not share the same definition, the two terms are also distinguished in terms of causality. Thus, the distinction between impairment and disability also relates to their relationship, or rather the lack thereof, and specifically the absence of a causal link between them. Not only is it suggested that disability *is* not impairment, but also that disability is not *caused* by impairment. The lack of a connection between impairment and disability is evident in the UPIAS document, as it is explicitly stated that disability is 'caused by a contemporary social organisation which takes no or little account of people who have physical impairments'.[24] It is therefore clear that, according to the UPIAS understanding, disability is socially imposed on people with impairments. The cause of disability, which is defined as the restriction of activity of people with impairments, is not impairment, but society's failure to include them in social activities. Importantly, it is the distinction in *that* sense that constitutes, as mentioned above, the unique feature of the British social model of disability.

The second characteristic of disability found in the UPIAS document is its understanding as the social oppression of people with impairments. UPIAS views disability in terms of social relations and refers in particular to the relationship between two groups of people. However, this relationship is viewed as only having negative aspects and it is therefore argued that people with impairments are subject to social oppression by those without impairments. Thus, having being 'disconnected' from impairment, disability is understood as the disadvantage experienced by people with impairments due to their social exclusion; since it is society that creates this disadvantage, disability is seen as a form of social oppression.

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[22] UPIAS, *Fundamental Principles of Disability* (n 12) 20.

[23] ibid.

[24] ibid.

The UPIAS understanding of disability and impairment was subsequently adopted by other disabled people's organisations, including Disabled People's International (DPI), an international body of national organisations of disabled people, and the British Council of Organisations of Disabled People (BCODP), the umbrella body for disabled people's organisations in the United Kingdom. It is important to note at this point that, although the definition of impairment initially concerned only physical conditions, it later included all types of impairment.[25] This is evident in the definitions adopted by DPI in 1982, which also endorsed the separation of impairment and disability:

> *Impairment* is the functional limitation within the individual caused by physical, mental or sensory impairment.
>
> *Disability* is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.[26]

Impairment – physical, as well as mental or sensory - is therefore distinguished from disability. Although both are defined as limitations, the former is described in medical terms whereas the latter is described in social terms. Furthermore, no causal link exists between them, since disability does not result from impairment but is rather created by barriers to participation in society. Interestingly, disability as defined by the DPI may be experienced even by individuals without impairments. However, as Bickenbach and others have noted, this seems to suggest that anyone who is excluded from participation in society may be regarded as disabled.[27]

Conceptualisation from Oliver

Influenced by the ideas found in the UPIAS document, Michael Oliver decided to develop a framework for the distinction between impairment and disability. To that end, he conceptualised in 1983 the 'social model of disability' and distinguished it from the 'individual model of disability'.[28] The latter is underpinned by the idea of 'personal tragedy', whereas the former is based on the theory of 'social oppression'.[29]

It should be noted at this point that medical approaches to disability are usually referred to as the 'medical model' of disability. According to this approach, disability is considered an individual deficit and is seen from a biomedical perspective as the outcome of impairment. It is understood in terms of functional limitations which require medical solutions; accordingly, the appropriate responses include prevention, cure, treatment and care. The 'social' model is more commonly contrasted to this 'medical' model of disability. Nevertheless, Oliver avoids the use of that term and rather refers to the 'individual' model. His view, as stated in *Understanding Disability*, is that 'there is no such thing as the medical model of disability'; there is instead medicalisation,[30]

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[25] Colin Barnes, 'Understanding the Social Model of Disability: Past, Present and Future' in Nick Watson, Alan Roulestone and Carol Thomas (eds), *Routledge Handbook of Disability Studies* (Routledge 2012) 14.

[26] Disabled Peoples' International (DPI), *Proceedings of the First World Class Congress* (Disabled Peoples' International 1982).

[27] Jerome Bickenbach and others, 'Models of Disablement, Universalism and the International Classification of Impairments, Disabilities and Handicaps' (1999) 48 Social Science & Medicine 1173, 1176.

[28] Oliver, *Understanding Disability* (n 13) 30.

[29] Oliver, *The Politics of Disablement* (n 13) 1.

[30] The 'medicalisation' of disability refers to the dominance of medical explanations for disability and reliance on medical expertise regarding that issue. It is linked to the rise and growth of medicine and

which, albeit significant, is merely an aspect of the individual model.[31] He similarly states in *The Politics of Disablement* that individualism is the 'core' ideology that determines how disability is understood, whereas medicalisation is a 'peripheral' ideology which makes disability 'a particular kind of problem'.[32]

According therefore to Oliver's conceptualisation, disability can be viewed either from an 'individual' or from a 'social' perspective. The individual model views the problem as located in the individual and caused by functional limitations, whereas the social model views it as located within society and caused by society's failure to address the needs of persons with impairments.[33] The 'social model' approach places great emphasis on the 'disabling' environment which excludes people with impairments from participation in society. Disability is therefore understood as the consequence of externally imposed barriers to social inclusion. Finkelstein argues in *Attitudes and Disabled People* that, as long as social barriers to the reintegration of persons with impairments are not removed, disability will continue to exist. Accordingly, social action is required and particularly 'changes in society, changes to the environment, changes in environmental control systems, changes in social roles, and changes in attitudes by people in the community as a whole'.[34] Oliver similarly states that the purpose of the social model is to draw attention, not to functional limitations of persons with impairments, but to the economic, environmental and cultural barriers they face, such as inaccessible education systems and transport, discriminatory health services and negative attitudes.[35]

The 'social model' approach takes the view that economic and social forces create disability, and that consequently the appropriate response for its elimination is the removal of disabling barriers to participation in society. It is based on radical ideas that describe disability in terms of social oppression, and deny any causal link between disability and impairment. It should finally be noted that although it has exercised great influence on disabled people and their organisations, as well as disability studies,[36] it has been widely criticised over recent years for its limitations, even within disability studies.[37] Consequently, the 'social model' approach is still evolving, although it has

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the medical profession, and particularly to the role of medicine as a mechanism for social control. For Oliver's view on medicalisation, see Oliver, *The Politics of Disablement* (n 13) 49-54; Michael Oliver and Colin Barnes, *The New Politics of Disablement* (2nd edn, Palgrave Macmillan 2012) 83-85. See also Barnes and Mercer, *Exploring Disability* (n 14) 59-63.

[31] Oliver, *Understanding Disability* (n 13) 31.

[32] Oliver, *The Politics of Disablement* (n 13) 46, 58.

[33] Oliver, *Understanding Disability* (n 13) 32.

[34] Finkelstein (n 18) 22.

[35] Mike Oliver, 'The Social Model in Action: If I Had a Hammer' in Colin Barnes and Geof Mercer (eds), *Implementing the Social Model of Disability: Theory and Research* (The Disability Press 2004) 6 <http://disability-studies.leeds.ac.uk/files/library/Barnes-implementing-the-social-model-chapter-2.pdf> accessed 31 July 2017.

[36] For an overview of the social model's major influences on disability studies and disability policy, see Barnes, 'Understanding the Social Model of Disability: Past, Present and Future' (n 25) 17-21.

[37] For an overview of the main criticisms of the social model, see Carol Thomas, 'Rescuing a Social Relational Understanding of Disability' (2004) 6 Scandinavian Journal of Disability Research 22, 25-27. Tom Shakespeare summarises the debates around, and makes his own critique of, the social model: see Shakespeare, *Disability Rights and Wrongs* (n 16) 34-50. See also Tom Shakespeare, *Disability Rights and Wrongs Revisited* (2nd edn, Routledge 2014) 21-42. Also, note in particular the criticisms made by feminist writers such as Jenny Morris, Liz Crow and Sally French: see Jenny Morris, *Pride against Prejudice: Transforming Attitudes to Disability* (Women's Press 1991); Liz Crow, 'Including All of Our Lives: Renewing the Social Model of Disability' in Colin Barnes and Geof Mercer (eds) *Exploring*

not abandoned its unique characteristic, namely the idea that disability is caused by social and environmental barriers to inclusion and participation in society, rather than impairment.

The following Part will examine a more balanced - in the sense that it combines medical and social understandings - approach to disability than the British 'social model', found in WHO's International Classification of Functioning, Disability and Health (ICF).[38]

III. WHO'S INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (2001)

The purpose of this Part is to identify how disability is understood in the ICF, in order to assess in the following Part the connection between this understanding and the definition of disability in the CRPD.

The ICF is a classificatory instrument for the description of health and health-related states.[39] The ICF, as well as its previous version, namely the International Classification of Impairments, Disabilities and Handicaps (ICIDH),[40] are examples of the significant changes that were brought to international understandings of disability by the development and influence of the social approach to disability. However, although they recognise its social aspect, both ICIDH and ICF conceptualise disability as multi-dimensional and can therefore be considered balanced accounts.

As explained below, disability is described in the ICF not as restriction of ability to perform activities, but as the experience of difficulty at one or more of three levels of human functioning, namely at the body, person, or social level. It is therefore experienced as problems in body function or structure, in executing activities, or in involvement in life situations respectively. Furthermore, these problems arise from the interaction between the underlying health condition and contextual factors, namely features of the physical, social, and attitudinal environment as well as personal attributes.[41] This understanding of disability acknowledges the various factors that are relevant to the experience of people with impairments, and the relationship between these factors. Before considering in more detail the conceptualisation of disability in the ICF, it would be useful first to examine how disability was conceptualised in the ICIDH and how that understanding was influenced by the social approach.

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the Divide: Illness and Disability (The Disability Press 1996); Sally French, 'Disability, Impairment or Something in Between?' in John Swain and others (eds), *Disabling Barriers – Enabling Environments* (SAGE 1993).

[38] WHO, *ICF* (n 9).

[39] The ICF belongs to the WHO's 'family' of international classifications. The other major classification is the ICD-10: WHO, *International Statistical Classification of Diseases and Related Health Problems: Tenth Revision (ICD-10)*, endorsed in May 1990, Res. WHA 43.24 of the 43rd World Health Assembly (WHO 1992). Note the difference between the ICD-10 and the ICF: The ICD-10 provides an etiological framework for the classification, by diagnosis, of diseases, disorders and other health conditions, whereas the ICF provides a framework for the classification of functioning and disability associated with health conditions.

[40] WHO, *International Classification of Impairments, Disabilities and Handicaps (ICIDH)*, endorsed in May 1976, Res. WHA 29.35 of the 29th World Health Assembly (WHO 1980, rpt in 1993).

[41] For the overview of the ICF, see WHO, *ICF* (n 9) 11. For a short and helpful description of the ICF conception of disability, see WHO and the World Bank, *World Report on Disability* (WHO 2011) 5.

The International Classification of Impairments, Disabilities and Handicaps (ICIDH)

The ICIDH was published for field trial purposes in 1980 and was a classificatory instrument for the 'consequences of disease (as well as of injuries and other disorders) and of their implications for the lives of individuals'.[42]

There were three main classifications in the ICIDH, namely impairment, which represented 'disturbances at the organ level', disability, which reflected 'disturbances at the level of the person' and handicap, which reflected 'interaction with and adaptation to the individual's surroundings'.[43] Specifically, impairment was defined as 'any loss or abnormality of psychological, physiological, or anatomical structure or function',[44] disability as 'any restriction or lack … of ability to perform an activity in the manner or within the range considered normal for a human being'[45] and handicap as 'a disadvantage for a given individual … that limits or prevents the fulfilment of a role that is normal … for that individual'.[46] Regarding the relationship between them, disability was considered the result of impairment and handicap the result of impairment or disability.[47]

The ICIDH therefore distinguishes between impairment, disability and handicap. Interestingly, as Bickenbach and others note, the British 'social model' definition of disability is very similar to the ICIDH definition of handicap.[48] Both terms refer to the social exclusion and disadvantage experienced by persons with impairments; nevertheless, the ICIDH understands social disadvantage as the consequence of disability, whereas the 'social model' approach understands it as the cause of disability. Thus, whilst the ICIDH recognises three levels of the experience relating to disease or other health conditions, the 'social model' approach only accepts the existence of impairment and disability; the latter is defined not as restriction of activity, but rather as the disadvantage created by social and environmental barriers.

Furthermore, the ICIDH explicitly recognised that people with impairments experience social disadvantage, and the role of social and environmental factors in that experience, and can therefore be considered as a positive step towards the development of a social understanding of disability. As Mike Bury states, those who developed the ICIDH took the view that 'the WHO was moving away from a narrow medical model of health and disease … to one which recognised the consequences of health-related phenomena'.[49] The ICIDH drew attention to the social consequences of impairment, and, although it did not entirely adopt the 'social model' approach, it did pose challenges to the medical model of disability.

However, the ICIDH was seen by the proponents of the 'social model' approach as reflecting the ideas of the medical model, because of the relationship between the three categories and particularly the causal link between impairment and disability.[50]

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[42] WHO, *ICIDH* (n 40) 1.
[43] ibid 14.
[44] ibid 27.
[45] ibid 28.
[46] ibid 29.
[47] ibid 28-29.
[48] Bickenbach and others (n 27) 1177.
[49] Mike Bury, 'A Comment on the ICIDH2' (2000) 15 Disability and Society 1073, 1073.
[50] See Finkelstein (n 18); Oliver, *The Politics of Disablement* (n 13).

It seems indeed that the ICIDH failed to recognise that social and environmental barriers may also have disabling effects, and may therefore create disadvantage for people with impairments. The one-way causal connection between impairment, disability and handicap appears problematic, which is why this linear progression was later changed in the ICF. As explained in particular in the foreword to the 1993 reprint, the ICIDH needed to be revised mainly in order to address problems regarding the relationship between the three categories and also to draw more attention to the role of environment in the development of handicap.[51]

The International Classification of Functioning, Disability and Health (ICF)

The revised version of the ICIDH, namely the ICF, was published by WHO in 2001. The ICF is 'a multipurpose classification intended to serve various disciplines and different sectors'[52] and its aim is to offer 'a unified and standard language and framework for the description of health and health-related states'.[53] It is now a classification of the 'components of health'; it is no longer concerned, as the ICIDH was, with the 'consequences' of disease.[54] The problematic aspects of the ICIDH regarding the causes of disability are therefore avoided in the ICF, which rather 'takes a neutral stand with regard to etiology'.[55]

The ICF provides a framework for 'situations with regard to human functioning and its restrictions',[56] and describes a wide range of experiences, both negative and positive. Importantly, the understanding of disability is changed; whilst in the ICIDH disability was described as restriction of ability to perform activities, it now refers to problems in functioning. In particular, the ICF defines disability as 'an umbrella term for impairments, activity limitations and participation restrictions'.[57] Thus, as Bickenbach states, disability is viewed as 'parasitical on positive, multidimensional notions of human functioning'.[58]

The ICF identifies three levels of human functioning, namely the body, person, and social level; disability is conceptualised as the experience of difficulty in one or more of them. The concepts that indicate problematic aspects of health are included in the first part of the ICF, which is called 'Functioning and Disability'.[59] These are in particular 'impairments', which are 'problems in body function or structure'; 'activity limitations', which replace the ICIDH term 'disabilities' and are 'difficulties in executing activities'; and 'participation restrictions', which replace the ICIDH term 'handicaps' and are 'problems in involvement in life situations'.[60]

One significant development in the ICF is the recognition of the multi-dimensional character of disability. The ICF is therefore based on a 'synthesis' of the medical and

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[51] WHO, *ICIDH* (n 40) 4.

[52] WHO, *ICF* (n 9) 5. For a summary of the aims and applications of the ICF, see WHO, *ICF* (n 9) 5, 6.

[53] ibid 3.

[54] ibid 4.

[55] ibid.

[56] ibid 7.

[57] ibid 213.

[58] Jerome Bickenbach, 'The International Classification of Functioning, Disability and Health and its Relationship to Disability Studies' in Nick Watson, Alan Roulestone and Carol Thomas (eds), *Routledge Handbook of Disability Studies* (Routledge 2012) 53.

[59] WHO, *ICF* (n 9) 8.

[60] ibid 10.

social models of disability; it integrates in particular all the aspects of functioning by adopting a 'biopsychosocial' approach.[61] This term is more commonly associated with George Engel, who used it in 1977 when he argued for the need to abandon the traditional biomedical model of disease and advance instead a 'biopsychosocial model'.[62] In particular, he saw the former as reductionist and therefore claimed that it is insufficient for understanding what causes diseases and how they can be treated. As he stated, it places too much emphasis on biology and 'leaves no room within its framework for the social, psychological, and behavioral dimensions of illness'.[63] In adopting this approach, the ICF takes the view that the experience of disability depends on biological, individual and societal factors.

Another significant development in the ICF is that it avoids making any direct causal links between impairment and disability; its conceptualisation is instead interactional. In particular, a person's disability, as well as functioning, 'is conceived as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors'.[64] Thus, focus is placed on the whole experience associated with a health condition. The ICF therefore departs from the ICIDH linear conceptualisation and suggests that the components of health interact with one another. The contextual factors are described in the second part of the ICF and are personal, which are not classified, and environmental. The environmental factors that are relevant in determining disability are barriers that exist in the physical, social or attitudinal environment and may be individual or societal. Individual factors include settings such as home, workplace and school, whereas societal include organisations and services related to the work environment, community activities, communication and transportation services, and informal social networks as well as laws, regulations, attitudes and ideologies.[65]

As a final point, it should be mentioned that the ICF, in spite of the revision process, has still been subject to considerable criticism.[66] It is important to emphasise, however, that the ICF does not adopt a medical model of disability. It is based on a 'biopsychosocial' approach, which views disability from various perspectives, combines medical and social understandings and recognises the relevance of a number of different factors to the experience of disability.

IV. THE DEFINITION OF DISABILITY IN THE CRPD

As explained in the previous Parts, the British 'social model' approach understands disability as a social situation, and particularly a form of social oppression imposed on people with impairments, which is caused by social and environmental barriers that exclude them from participating in society and which is entirely distinguished from their

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[61] ibid.

[62] George Engel, 'The Need for a New Medical Model: A Challenge for Biomedicine' (1977) 196 Science 129. Note that, as Nassir Ghaemi states, the term actually originated in 1954 and was invented by Roy Grinker, who 'applied it to psychiatry to emphasise the "bio" against psychoanalytic orthodoxy'; Engel then used it in 1977 to privilege the 'psychosocial' over the 'bio': Nassir Ghaemi, 'The Rise and Fall of the Biopsychosocial Model' (2009) 195 The British Journal of Psychiatry 3, 3.

[63] ibid 130.

[64] WHO, *ICF* (n 9) 8.

[65] ibid 17.

[66] For an overview of critiques of the ICF, see Bickenbach, 'The International Classification of Functioning, Disability and Health and its Relationship to Disability Studies' (n 58) 60-63. See also Barnes and Mercer, *Exploring Disability* (n 14) 38-40.

individual impairment. On the other hand, the ICF describes disability as the multi-dimensional and interactive experience of a wide range of difficulties in functioning; in particular, these difficulties include impairments, limitations in performing activities and restrictions in participating in life situations, and arise out of the complex interaction between health conditions, personal factors and barriers in the physical and social environment.

Having identified how disability is understood under the 'social model' approach and in the ICF, this Part will now determine which understanding aligns more closely to the definition of disability in the text of the CRPD.[67]

The definition of disability in the final text of the CRPD

The relevant definition is found in the Preamble to the CRPD, which states that:

> [D]isability is an evolving concept and … results from the *interaction* between persons with impairments and attitudinal and environmental *barriers* that *hinders* their full and effective participation in society on an equal basis with others.[68]

It would also be useful at this point to note that the ICF defines disability as follows:

> Disability … denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).[69]

In considering whether the definition of disability in the CRPD is closer to the British 'social model' or the ICF, two key observations can be made; one supports the argument that the CRPD adopts an understanding of disability similar to the ICF, and the other the argument that the CRPD does not adopt the British 'social model' approach.

The first observation concerns the use of the word 'interaction'. In particular, disability is defined in the CRPD as resulting from the *interaction* between persons with impairments and attitudinal and environmental barriers. This definition resembles the ICF conceptualisation of disability as the interaction between individuals with health conditions and their personal and environmental factors. Disability in both the CRPD and the ICF is understood dynamically, as an interactive process between individuals and their environment; it is also noteworthy that the CRPD uses the exact same word that is used in the ICF, namely 'interaction'. In contrast, the British 'social model' understands disability statically, as the result of social barriers that exclude people with impairments from participating in society. It therefore seems that the CRPD

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[67] Note that the CRPD, beyond the issue of whether or not it adopts the British 'social model', views disability from a human rights perspective, moving away from charity-based approaches. The shift from a 'charity' towards a 'human rights' approach was highlighted in the well-known study of Gerard Quinn and Theresia Degener on the UN protection of the human rights of people with disabilities. The human rights perspective on disability, as stated in the report, views people with disabilities as 'subjects' and not as 'objects'; not as 'problems', but as 'holders of rights': Gerard Quinn and Theresia Degener, *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability* (United Nations 2002) 1.

[68] CRPD, Pmbl, para (e) (emphasis added). Note that there is some uncertainty as to the role and importance of a Preamble in international law: see for example Max Hulme, 'Preambles in Treaty Interpretation' (2016) 164 U Pa L Rev 1281.

[69] WHO, *ICF* (n 9) 213.

defines disability in a way that aligns more closely to the ICF than the British 'social model' approach.

The second observation concerns the use of the word 'hinders' in the CRPD. In particular, the definition of disability contains a relative clause, which reads: 'that *hinders* their full and effective participation in society on an equal basis with others'. In order to determine whether the CRPD adopts the British 'social model' approach or not, it is important to identify whether that clause relates to the noun 'interaction', or the noun 'barriers'; thus, whether it is the attitudinal and environmental barriers that hinder participation in society, or the interaction between persons with impairments and these barriers. Since the CRPD uses the singular form of the verb 'hinder', there can be no doubt that it relates to the also singular word 'interaction', instead of the plural 'barriers'. Therefore, the view taken in the CRPD is that the participation of persons with impairments in society is hindered by the interaction between these persons and attitudinal and environmental barriers. Importantly, it is not the barriers that hinder participation in society, but rather the interaction between persons and barriers. This is not, however, the approach adopted by the British 'social model'. In particular, the British 'social model' suggests that social participation is only hindered by the presence of disabling barriers; thus, persons with impairments have nothing to do with the social exclusion they face, and no connection or interaction exists between them and the barriers that prevent them from participating in society. Had the CRPD wished to adopt this approach, it would have used the plural form of the verb 'hinder', in order to emphasise that social exclusion is caused only by disabling barriers.[70]

It is also important to note that it would be wrong to assume that the use of the word 'barriers' in the CRPD definition points towards the adoption of the British approach; although this particular term has been associated with the 'social model of disability',[71] it is *also* used in the ICF. In particular, the ICF recognises the relevance of environmental factors to human functioning or disability, and uses the term 'barriers' to denote the negative effects of the environment - as opposed to 'facilitators', which are positive effects of the environment.[72]

Based on the above considerations, it can be argued that the CRPD does not adopt the British 'social model' approach to disability, but rather defines disability in a way similar to the ICF understanding. This argument has also been made by Jerome Bickenbach, who stated in 2009 that 'the link between the ICF conception of disability and CRPD is obvious upon inspection',[73] and again in 2012 that 'the ICF conceptualization does surface in the preamble of the CRPD'.[74] However, the connection between the CRPD and the ICF has often been overlooked in the CRPD

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[70] To clarify, the sentence in that case would read: 'Disability … results from the interaction between persons with impairments and attitudinal and environmental barriers that *hinder* their full and effective participation in society on an equal basis with others.' Thus, the verb 'hinder' would relate to the noun 'barriers' and it would be clear that it is the barriers that hinder participation in society, not the interaction between these barriers and persons with impairments.

[71] See for example the DPI definition of disability: DPI (n 26); John Swain and others (eds), *Disabling Barriers – Enabling Environments* (SAGE 1993). See also Finkelstein (n 18) 22.

[72] WHO, *ICF* (n 9) 22, 171. For the full definition of 'barriers', see WHO, *ICF* (n 9) 214.

[73] Jerome Bickenbach, 'Disability, Culture and the UN Convention' (2009) 31 Disability and Rehabilitation 1111, 1112.

[74] Bickenbach, 'The International Classification of Functioning, Disability and Health and its Relationship to Disability Studies' (n 58) 60.

literature; in fact, as will be seen below, many authors seem to hold the mistaken view that the CRPD adopts the so-called 'social model of disability'.

It should be noted at this point that there can be some confusion regarding the meaning of the term 'social model of disability'. As mentioned in Part II, the 'social model of disability' is a unique, strong social approach to disability, developed in Britain in the 1970s and 1980s. It denies any causal link between impairment and disability and suggests in particular that disability is entirely caused by social barriers that prevent people with impairments from participating in society. The British 'social model' approach is very well known and most authors are familiar with it. It would therefore be reasonable to assume that they use the term 'social model of disability' correctly, as a reference to the British approach.

However, this term is sometimes used in the wrong way. As already mentioned, the British 'social model' is only one of the various social approaches to disability that have been developed; others include the Nordic 'relational' understanding and the North America 'minority group' approach. These are weaker approaches, and they do not share the special characteristics of the British 'social model'. They simply emphasise the role of society and the environment in creating disability, without entirely rejecting its medical or individual aspects. However, because of the popularity of the British approach, the term 'social model of disability' might be used, incorrectly, as a general reference to approaches that view disability from a social perspective, without intention to specifically refer to the British approach. Thus, some authors might use the term 'social model', when they would actually mean 'social approach'.

As noted above, there seems to be a mistaken view that the CRPD adopts the 'social model of disability'. In the examples mentioned below, the authors use the term 'social model'; it is not clear, however, what they mean by using that term. They could refer to the British approach, or they could simply imply that the CRPD generally adopts a social approach to disability. As previously stated, the former possibility is more probable and it will therefore be assumed that, by using the term 'social model', they refer to the British approach. Nevertheless, it can be argued that in any case this view is wrong. If they refer specifically to the British 'social model', they are mistaken because, as already found, the CRPD does not adopt this approach. If they generally refer to a social approach, they are mistaken too. The statement that the CRPD adopts a social approach to disability, albeit not entirely wrong, is inaccurate; the CRPD, as found above, adopts an approach which seems closer to the ICF 'biopsychosocial' approach to disability. It would therefore be inadequate to simply state that it adopts a social approach, because it actually adopts an approach which is based on a 'synthesis' of the medical and social 'models' of disability.[75]

Before mentioning a few examples of authors who misinterpret the CRPD definition of disability, it is worth noting an author who describes it correctly. Eilionóir Flynn states that the definition of disability adopted in the CRPD is 'based on the understanding that disability is not solely the result of a medical impairment, but also stems from societal barriers to participation'.[76] Flynn refers to 'societal barriers', but carefully avoids mentioning the 'social model'. Furthermore, by using the word 'solely', she

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[75] WHO, *ICF* (n 9) 10.

[76] Eilionóir Flynn, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities* (CUP 2011) 18.

recognises that the CRPD understanding is that disability is caused by both impairment and barriers. Therefore, despite the lack of reference to the ICF, her statement is entirely accurate and consistent with the language of paragraph (e) of the Preamble.

Usually, however, the definition of disability in the CRPD is misunderstood. Rosemary Kayess and Phillip French state in *Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities*, which is one of the leading texts on the CRPD, that:

> [P]aragraph (e) of the Preamble makes it clear that disability is to be understood according to the precepts of the social model. 'Disability' is conceptualised as the product of the interaction of persons with impairments with environmental barriers that hinder their full and effective participation in society on an equal basis with others.[77]

Stefan Trömel also notes that 'the paragraph in the preamble provides a social model definition of disability, based on the interaction between impairment and barriers'.[78] Charles O' Mahony states that 'there is no doubt that the CRPD has adopted the approach of the social model of disability'.[79] Shivaun Quinlivan and Peter Bartlett refer to the definition of persons with disabilities, found in Article 1 of the CRPD, which reads:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.[80]

It is worth noting that in this definition, the verb 'hinder' clearly relates to the noun 'impairments'. Therefore, like paragraph (e) of the Preamble to the CRPD, Article 1 too recognises that impairments - in interaction with various barriers - may hinder persons with disabilities' participation in society. This is the view adopted in the ICF rather than the British 'social model'. However, Quinlivan states that 'this definition clearly endorses the social model of disability' and goes on to say that 'the focus of this definition is on the barriers and obstacles that hinder or prevent full, equal and effective participation in society …'[81] Bartlett similarly states that 'the reference to barriers to participation emphasises the social model of disability adopted by the CRPD'.[82]

Kayess and French, Quinlivan, O' Mahony, Trömel and Bartlett all strongly suggest that the CRPD adopts the 'social model' of disability. The first two go so far as to argue

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[77] Rosemary Kayess and Phillip French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 HRL Rev 1, 24.

[78] Stefan Trömel, 'A Personal Perspective on the Drafting History of the United Nations Convention on the Rights of Persons with Disabilities' in Gerard Quinn and Lisa Waddington (eds), *European Yearbook of Disability Law: Volume 1* (Intersentia 2009) 121.

[79] Charles O'Mahony, 'Legal Capacity and Detention: Implications of the UN Disability Convention for the Inspection Standards of Human Rights Monitoring Bodies' (2012) 16 The International Journal of Human Rights 883, 885.

[80] CRPD, Art 1.

[81] Shivaun Quinlivan, 'The United Nations Convention on the Rights of Persons with Disabilities: An Introduction' (2012) 13 ERA Forum 71, 76.

[82] Peter Bartlett, 'The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law' (2012) 75 MLR 752, 758.

that this is *clear*,[83] and O' Mahony states that *there is no doubt* about it.[84] As already explained, however, it is far from clear and highly doubtful that disability in the CRPD is understood in accordance with the British 'social model' approach. It is interesting to note that Kayess and French and Quinlivan incorrectly state that, according to the CRPD understanding of disability, participation in society is hindered by the various barriers; however, as mentioned above, the CRPD understanding is that social participation is hindered by the interaction between persons with impairments and disabling barriers. It can therefore be argued that a close examination of the actual wording of the CRPD shows that it resembles the ICF conceptualisation of disability.

The reason why the ICF has not been explicitly endorsed in the CRPD is possibly because of the significant disagreement and the concerns that were expressed during the CRPD negotiations. In particular, the adoption of the ICF understanding was opposed by those in favour of a more radical approach to disability, such as the British 'social model'. This has been acknowledged by Kayess and French, who note that 'any attempt to use the ICF to interpret the CRPD will inevitably be fraught with controversy',[85] and also by Bickenbach, both in 2009 and 2012. In particular, Bickenbach mentioned in 2009 that 'the political environment surrounding the drafting of CRPD made the explicit adoption of the ICF conception politically inexpedient',[86] and in 2012 that the ICF is 'never referenced and only paraphrased'[87] in the CRPD. It is therefore useful to examine now the discussion that took place during the CRPD negotiations regarding the definition of disability.

The discussion on the definition of disability during the CRPD negotiations

The negotiations of the CRPD were conducted by the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (Ad Hoc Committee).[88] The Ad Hoc Committee met in eight sessions; the process of negotiation and drafting began in August 2002 and ended in December 2006.

During its Second Session, held from 16 to 27 June 2003, the Ad Hoc Committee decided to establish a 'Working Group',[89] with the task to draft a text of a convention on the rights of persons with disabilities. This decision was endorsed by the General Assembly in its Resolution 58/246 of 23 December 2003.[90] The 'Working Group' met from 5 to 16 January 2004 and, based on that draft text, the Member States and

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[83] Kayess and French (n 77) 24; Quinlivan (n 81) 76. Note that Kayess and French mention that the 'social model' influenced the development of the CRPD primarily as a 'disability rights manifesto', rather than a 'theory of disability'. As they explain, the former tends to see disability from a 'radical social constructionist view ... in which impairment has no underlying reality': Kayess and French (n 77) 7.

[84] O'Mahony (n 79) 885.

[85] Kayess and French (n 77) 24.

[86] Bickenbach, 'Disability, Culture and the UN Convention' (n 73) 1112.

[87] Bickenbach, 'The International Classification of Functioning, Disability and Health and its Relationship to Disability Studies' (n 58) 60.

[88] Resolution on a Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities, 19 December 2001, UN Doc. A/RES/56/168, 26 February 2002.

[89] Report of the Ad Hoc Committee on its Second Session, 3 July 2003, UN Doc. A/58/118 and Corr. 1, para 15.

[90] Resolution on the Ad Hoc Committee, 23 December 2003, UN Doc. A/RES/58/246, 11 March 2004, para 3.

observers negotiated in the following sessions the final text of the CRPD. Also, following the Sixth Session and pursuant to General Assembly Resolution 60/232 of 23 December 2005,[91] the Chairman of the Ad Hoc Committee (Don MacKay, Ambassador of New Zealand) prepared a draft text that was considered during the Seventh Session, held from 16 January to 3 February 2006.

The fact that the definition of disability was the subject of much debate during the negotiations is well documented.[92] The 'Working Group' draft text intended to define disability in the Definitions Article (then draft Article 3), alongside the other definitions; the term was nevertheless left undefined. Instead, it was stated in the footnote that:

> Many members of the Working Group … suggested that the term 'disability' should be defined broadly. Some members were of the view that no definition of 'disability' should be included in the Convention, given the complexity of disability and the risk of limiting the ambit of the Convention. Other delegations pointed to existing definitions used in the international context, including the [ICF]. There was general agreement that if a definition was included, it should be one that reflected the social model of disability, rather than the medical model.[93]

During the Third Session, the Ad Hoc Committee undertook a reading of the 'Working Group' draft text; it was decided however not to consider Article 3, but to defer discussion to the next Session.[94]

The definition of disability in draft Article 3 was considered during the Fourth Session of the Ad Hoc Committee. Importantly, there was significant disagreement not only as regards the proper definition of disability, but also the question of whether disability should be defined at all in the convention. It would be useful to note now the main points that were made. The delegation from the Netherlands (on behalf of the EU) argued against definitions of 'disability' or 'persons with disabilities', on the basis that 'they risk becoming exclusive instead of inclusive'.[95] The delegation from Canada also noted that 'definitions on disability tend to change … and it will be difficult to come up with a definition of disability that stands the test of time'.[96] On the other hand, the delegation from Australia supported defining disability, but suggested that it should be 'broad and inclusive'.[97] The delegation from the National Human Rights Institutions also warned that 'there is a danger in not defining disability – States may refuse to ratify the convention if its meaning and obligations are uncertain'.[98] Regarding the approach taken in relation to disability, the delegation from Australia stated that, the importance of the 'social model of disability' notwithstanding, 'disability seen purely as

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[91] Resolution on the Ad Hoc Committee, 23 December 2005, UN Doc. A/RES/60/232, 31 January 2006, para 4.

[92] Arlene Kanter, 'The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities' (2006-2007) 34 Syracuse J Int'l L & Com 287, 291; Anna Lawson, 'The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?' (2006-2007) 34 Syracuse J Int'l L & Com 563, 593; Kayess and French (n 77) 23; Gerard Quinn, 'A Short Guide to the United Nations Convention on the Rights of Persons with Disabilities' in Gerard Quinn and Lisa Waddington (eds), *European Yearbook of Disability Law: Volume 1* (Intersentia 2009) 101.

[93] Report of the Working Group to the Ad Hoc Committee, 27 January 2004, UN Doc. A/AC.265/2004/WG.1, fn 12.

[94] Daily Summary of Discussion at the Third Session, 24 May 2004, Original MS Word version, 10 <http://www.un.org/esa/socdev/enable/rights/ahc3sum24may.htm> accessed 31 July 2017.

[95] Daily Summary of Discussion at the Fourth Session, 23 August 2004, Original MS Word version, 9-10 <http://www.un.org/esa/socdev/enable/rights/ahc4sum23aug.htm> accessed 31 July 2017.

[96] ibid 11.

[97] ibid.

[98] ibid 13-14.

a function of the environment would render a definition unworkable'.[99] The delegation from the Republic of Korea also pointed out that 'the definition of disability has evolved and ICF now embraces a broad, social model definition'.[100]

Article 3 and the definition of disability were not discussed during the Fifth and Sixth Sessions of the Ad Hoc Committee. The Chairman, in the draft text that he prepared for discussion at the Seventh Session, stated that:

> Views are divided as to whether it is necessary to define 'Disability' and 'Persons with disabilities'. I tend to think that we don't, as this will be very difficult, and there is a risk that we will unintentionally exclude someone.[101]

The Definitions Article (now Article 2) was discussed during the Seventh Session of the Ad Hoc Committee and included a lengthy debate regarding the definition of disability. The Chair, in summarising the relevant views heard, noted that there was still disagreement over the inclusion of such a definition in the convention; this issue could be addressed either by referencing a definition or the scope of the meaning of disability in the Preamble, or by including such a reference in the final report of the Ad Hoc Committee.[102] He recognised however that the 'overall consensus' would be to include a definition of disability in Article 2, and finally stated that 'a proposal addressing the issue would be forthcoming'.[103] Indeed, a possible definition of disability was later proposed by the Chair:

> 'Disability' results from the interaction between persons with impairments, conditions or illnesses and the environmental and attitudinal barriers they face. Such impairments, conditions or illnesses may be permanent, temporary, intermittent or imputed, and include those that are physical, sensory, psychosocial, neurological, medical or intellectual.[104]

It can be noted that the Chair's proposed understanding of disability, as resulting from the interaction between persons with impairments and the barriers they face, is in line with the ICF conceptualisation. It should also be noted that several delegations referred to the ICF understanding of disability during the discussion on the Definitions Article at the Seventh Session. In particular, the ICF was mentioned by the delegation from Australia as a possible source of a definition for disability.[105] The delegation from Australia also referred to the social model, but opposed the adoption of a 'strict social model approach' that would release States from their obligations towards persons with disabilities once the barriers created by society were removed.[106] The delegation from Serbia and Montenegro mentioned the ICF as well, and suggested a possible reference to the ICF, or the social model approach, in the Preamble.[107] The delegation from Norway supported Australia's proposal for a definition of 'disability' along the lines of the ICF and social model definitions, and stated that they would be 'flexible' about

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[99] ibid 11.

[100] ibid 10.

[101] Letter dated 7 October 2005 from the Chairman to all members of the Committee, 14 October 2005, UN Doc. A/AC.265/2006/1 para 17.

[102] Daily Summary of Discussion at the Seventh Session, 31 January 2006, Original MS Word version, 21 <http://www.un.org/esa/socdev/enable/rights/ahc7sum31jan.htm> accessed 31 July 2017.

[103] ibid.

[104] Possible Definition of 'Disability': Discussion Text Suggested by the Chair <http://www.un.org/esa/socdev/enable/rights/ahc7pddisability.htm> accessed 31 July 2017.

[105] Daily Summary of Discussion at the Seventh Session (n 102) 8.

[106] ibid.

[107] ibid 9.

including such a definition in the Preamble, as suggested by Serbia and Montenegro.[108] The delegation from Jamaica was drafting legislation on people with disabilities at the time, and mentioned that they 'had decided upon the WHO-ICF approach, which distinguishes between impairment, disability and handicap';[109] it should be noted however that the distinction between impairment, disability and handicap is made, not in the ICF, but in the ICIDH. The delegations from India and Chile also referred to the ICF in discussing the possible definition of disability.[110] Finally, the delegation from the International Disability Caucus (IDC)[111] described the ICF as 'very controversial' and noted that many disability organisations do not accept it as a definition of disability.[112] This lack of approval seems to be the reason why, as mentioned above, the similarity between the CRPD and the ICF understandings of disability, although readily apparent, is not expressly recognised either in the CRPD literature or the text itself.

During its Eighth and final Session, the draft text of a convention on the rights of persons with disabilities was concluded, and it was adopted by the Ad Hoc Committee on 25 August 2006. The Ad Hoc Committee then decided to establish an open-ended 'Drafting Group', with the task to ensure 'uniformity of terminology throughout the text of the draft convention, harmonising the versions in the official languages of the United Nations';[113] following that, on 5 December 2006 recommended to the General Assembly for adoption a draft resolution entitled 'Convention on the Rights of Persons with Disabilities'.[114]

Although the 'Drafting Group' produced four revised texts, the definition of disability in this draft convention was eventually adopted in the final text of the CRPD without a single modification. In particular, disability was defined in the preamble of the draft convention as follows:

> [D]isability is an evolving concept and ... results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others[115]

It is worth noting that in the first revised text of the 'Drafting Group', it was suggested to add a comma after the word 'barriers', 'to ensure that the phrase thereafter refers to "interaction" and not to "barriers".[116] Apparently, it was considered significant for the 'Drafting Group' to leave no doubt about the position in the CRPD regarding the cause of social exclusion and disability. This therefore supports the argument made above, namely that the CRPD takes the view that participation in society is hindered not by

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[108] ibid.

[109] ibid 14.

[110] ibid 15-16.

[111] The International Disability Caucus (IDC) was a coalition of international, regional, and national disabled people's organisations (DPOs) and allied non-governmental organisations (NGOs).

[112] Daily Summary of Discussion at the Seventh Session (n 102) 17.

[113] Interim Report of the Ad Hoc Committee on its Eighth Session, 1 September 2006, UN Doc. A/AC.265/2006/4, para 13.

[114] Final Report of the Ad Hoc Committee, 6 December 2006, UN Doc. A/61/611.

[115] Interim Report of the Ad Hoc Committee on its Eight Session (n 113) Annex II.

[116] Ad Hoc Committee, Draft Convention on the Rights of Persons with Disabilities and Draft Optional Protocol: First revised text, 13 September 2006, fn 3 <http://www.un.org/esa/socdev/enable/drafting.htm> accessed 17 July 2017.

barriers alone, but by the interaction between barriers and persons with impairments, and also that the difference between the two opposing views is actually meaningful.

The comments made in the second revised text - as well as the third and fourth texts - simply regarded the use of correct grammar. It was noted in particular that 'if a comma is put after barriers, in that case "that" must be replaced by "which"; there can be no comma in front of "that".[117] The editor also recommended putting a comma after 'interaction', if the comma after 'barriers' was to be kept.[118] In the third revised text, 'that' was still replaced by 'which', but the commas were omitted.[119] Finally, 'that' replaced 'which' in the fourth revised text of the 'Drafting Group', and therefore it was decided to maintain in the CRPD the old definition of disability.[120] It seems indeed that the proposed changes were not actually needed; in fact, if adopted, they would have made the meaning of the text less understandable.

The examination of the discussion on the definition of disability during the CRPD negotiations reveals that the Ad Hoc Committee intended to emphasise that disability is the result of the interaction between barriers and persons with impairments, which is the same way that the ICF understands disability. The proposals of the 'Drafting Group', as mentioned above, and especially their will to ensure that participation in society is hindered by both impairment and barriers, confirm that they adopt a different view than the British 'social model', which only regards disabling barriers as the cause of social exclusion. It therefore seems to be confirmed that the CRPD does not adopt the British 'social model' approach to disability, but rather defines disability in a way similar to the ICF understanding.

V. CONCLUSION

This article sought to determine whether the CRPD adopts the 'social model' approach to disability or not. To that end, it first examined the 'social model', which is the most commonly known social approach to disability. This understanding, developed in Britain during the 1970s and 1980s, rejects the view that disability is an individual and medical problem caused by impairment, and rather suggests that disability is a form of social oppression, caused only by social barriers that exclude people with impairments from participation in society.

It then went on to examine a more balanced - in the sense that it integrates medical and social understandings - approach to disability, found in the ICF. Adopting a 'biopsychosocial' approach, the ICF understands disability as multi-dimensional and interactive. Disability is conceptualised in particular as the experience of a wide range of problems in functioning, including impairments, limitations in performing activities

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[117] Ad Hoc Committee, Draft Convention on the Rights of Persons with Disabilities and Draft Optional Protocol: Second revised text, 3 October 2006, fn 4 <http://www.un.org/esa/socdev/enable/drafting.htm> accessed 31 July 2017.

[118] ibid. To clarify, the sentence read: ' … disability results from the interaction, between persons with impairments and attitudinal and environmental barriers, which hinders …'

[119] Ad Hoc Committee, Draft Convention on the Rights of Persons with Disabilities and Draft Optional Protocol: Third revised text, 10 October 2006 <http://www.un.org/esa/socdev/enable/drafting.htm> accessed 31 July 2017. The sentence read: ' … disability results from the interaction between persons with impairments and attitudinal and environmental barriers which hinders …'

[120] Ad Hoc Committee, Draft Convention on the Rights of Persons with Disabilities and Draft Optional Protocol: Fourth revised text, 30 October 2006 <http://www.un.org/esa/socdev/enable/drafting.htm> accessed 31 July 2017.

and restrictions in participating in life situations; this experience is seen as arising out of the complex interaction between a health condition, personal factors and barriers in the physical and social environment.

The article finally examined the definition of disability in the text of the CRPD. The CRPD defines disability as resulting from the interaction between persons with impairments and attitudinal and environmental barriers. It also states that this interaction hinders the full and effective participation of persons with impairments in society on an equal basis with others. On the basis of this definition, and particularly the use of the words ‘interaction’ and ‘hinders’, it was found that the CRPD does not adopt the British ‘social model’ approach, but rather defines disability in a way similar to the ICF understanding, although this similarity is often overlooked in the CRPD literature. The final part of the article focused on the discussion during the CRPD negotiations regarding the definition of disability. It was found that the Ad Hoc Committee was aware of the differences between the ‘social model’ and the ICF approaches to disability, especially in relation to its cause and consequences, and intentionally chose a definition which is closer to the latter.

Demonstrating that the CRPD defines disability, not on the basis of the ‘social model’, but in a way similar to the ICF understanding may have significant practical implications. The ‘social model’ has been widely criticised for its limitations, especially for the distinction it makes between impairment and disability and for considering impairment as being entirely irrelevant to the experience of disability. By being connected to the ‘social model’, the CRPD risks facing the same criticism, being met by governments and policy makers with scepticism or being dismissed. Associating the CRPD with the ICF might therefore facilitate its implementation. At the same time, the valuable insights of the ‘social model’ would not be lost, as the social dimension of disability and the disabling effect of social and environmental barriers are recognised by the ICF too. The medical dimension is also recognised by the ICF, as well as the relevance of impairment to the experience of disability and the health needs of persons with disabilities. Although highly controversial especially among persons with disabilities, recognising that disability also has a medical aspect should not necessarily be seen as negative and undesirable. Provided that care and treatment is not forced upon them, persons with disabilities might benefit from the connection between the CRPD and the ICF, as understandings of disability that incorporate medical factors have the advantage that, in addition to any relevant social responses, the health needs of persons with disabilities must also be addressed, and appropriate healthcare services must be available to them.

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NEGOTIATING RELATIONALITY: MENTAL CAPACITY AS NARRATIVE CONGRUENCE

DAVID GIBSON[*]

ABSTRACT

The concept of capacity that emerges from the Mental Capacity Act (2005) is conceptually flawed and places practitioners in an impossible situation regarding its application. The continued support by the UK government and others for the Act strengthens the idea that the capacity/incapacity distinction is natural and that incapacity is an intrapsychic feature of an individual. This paper proposes an alternative model for understanding capacity and its assessment based on a narrative theory that recognises the role of the practitioner and identity negotiation. Although this more nuanced approach may at first appear more complex, it avoids the conceptual and practical difficulties raised by the notion of mental capacity.

I. INTRODUCTION

The Mental Capacity Act 2005 (MCA) established a legal framework for the identification and classification of human action as either capacitous or incapacitous. This framework however can be understood in a broader context, as part of a movement in health and social care for greater protection of those experiencing vulnerability, whilst also empowering individuals to act with self-determination.[1] In outlining the conditions under which an individual's actions are to be respected but also under which interference is permitted, the MCA attempts to distinguish between autonomous and non-autonomous action. Where an individual is found to have capacity, they are permitted to have their actions respected and as such mental capacity is "gatekeeper to the right to autonomy".[2] The definition of capacity adopted in the MCA, the culmination of a lengthy deliberation, is but one of many definitions which could have underpinned capacity legislation. Although the Act has received political praise and support, at both its coming into law and by a House of Lords Select Committee in 2014, the argument can be made that for such a rigorously debated piece of legislation, considerable difficulties remain. The difficulty of achieving compliance or implementation is compounded by the non-binding status of the Code of Practice and the lack of a definitive guide for compliance with the MCA.[3] The recommendation that greater effort needs to be placed on achieving compliance has beckoned in considerable emphasis on training. The issue of implementation is itself subject to a more serious concern, namely whether it is possible to achieve what the Act sets out in the first place. The allocation of considerable financial resources to

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[1] It is this political and social agenda associated with the MCA that is considered "ground breaking", see T Williamson, 'Capacity to Protect – the Mental Capacity Act explained' (2007) 9(1) Journal of Adult Protection 31, or the "spirit of the MCA" in M Graham and J Cowley, *A Practical Guide to the Mental Capacity Act 2005: Putting The Principles of the Act Into Practice* (Jessica Kingsley Publishers, London, 2015) 16.

[2] M Donnelly, *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press, New York, 2010) 2.

[3] Department for Constitutional Affairs. *Mental Capacity Act 2005: Code of Practice* (TSO, London 2007).

training and implementation would appear questionable at the least, if it is unclear whether a capacity assessment in accordance with the Act can be performed.

The MCA arguably can be read as adopting a Millian understanding of the liberal self, inviting capacity to be considered in regard to liberty and non-interference.[4] The presence of capacity prohibits interference in an individual's action. The establishment in the MCA of a cognitivist two-stage assessment process for the identification of incapacity in respect of a decision at a specific time, places constraints on the attempt to justify interference in the life of another. The two-stage process is comprised of diagnostic and functional elements. For an individual to be found to lack capacity they must have an "impairment of, or a disturbance in the functioning of, the mind or brain" which leads to an inability to "understand the information relevant to a decision", "to retain this information", to use or weigh this information", and to "communicate his decision" or simply understanding, retention, weighing and communication (URWC).[5] Where assessment is called for, individuals with impairments of the mind or brain must demonstrate all four abilities in respect of a proposed decision to be held capacitous. As Catriona Mackenzie and Wendy Rogers observe however, the expectation of the MCA for mental capacity to be assessed at a specific time, (synchronically), is challenged by the parallel commitment to understand the self and consequently mental capacity over time, (diachronically).[6] In section 1 the principles for the application of the Act are set out. Principle 3 of the MCA requires that a person be engaged with over time and supported in making a decision, while in respect of best interests determinations in section 4(6) there is a requirement to consider the individual over time so that a best interests decision is founded on an appreciation of the individual's values, beliefs, etc. Further challenges to the MCA's understanding of the self cognitively and discretely are advanced in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and in approaches which view the MCA in a broader context of care and the promotion of self-determination.[7] The tension in the MCA between viewing the self cognitively at a specific time and viewing the self as having values and beliefs through time, coupled with the acknowledgment that capacity assessments consider an individual over time, suggest that incapacity is not located within an individual simply at a specific time.[8] The MCA can be read as relying on particular conceptions or philosophies of the self, some of which are inconsistent with each other, the demands of practice and other legal frameworks including the UNCRPD.[9]

The adoption of a narrative approach to selfhood allows for an interrogation of mental capacity practice and highlights inadequacies and limitations in the cognitivist

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[4] JS Mill, *On Liberty and other writings* (Cambridge University Press, Cambridge, 1989) 13.

[5] Department of Health. Mental Capacity Act. (HMSO, London 2005) Part 1, Section 2(1) & 3(1).

[6] C Mackenzie and W Rogers, 'Autonomy, Vulnerability and Capacity: a philosophical appraisal of the Mental Capacity Act' (2013) 9 (Special Issue 1) International Journal of Law in Context 37-52.

[7] See P Bartlett, 'The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law' (2012) 75(5) Modern Law Review 752-778; Gerard Quinn. "Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD." Paper presented at HPOD Conference, Harvard Law School, Cambridge, MA, USA, 20 February 2010.

[8] S Stefan, 'Silencing the Different Voice: Competence, Feminist Theory and Law' (1993) 47 U. Miami Law Review, 766 and Donnelly, above, n 2, 147.

[9] This paper does not seek to address the compatibility between the MCA and UNCRPD. For such a discussion see L Series, 'Relationships, Autonomy and Legal Capacity: Mental Capacity and Support Paradigms' (2015) International Journal of Law and Psychiatry 80-91.

approach of the MCA. Paul Ricoeur's understanding of narrative identity, as developed in *Time and Narrative* and *Oneself as Another*, allows for mental capacity practice to be evaluated from a perspective distinct from both the cognitive model of the MCA and recent relational approaches to mental capacity.[10] Ricoeur argues that the activity of narrative identity, as something we engage in alongside others, is that which provides integrity or coherence to people's lives by drawing together different aspects of experience.[11] Crucially though, narrative is inter-subjective and can thus be seen as posing a challenge to the individualistic understanding of the self espoused in the MCA. The problems associated with implementing the MCA including instigating capacity assessment, assessing functional understanding, assessor bias and in particular the call for understanding capacity as internal to an individual and the requirement to view the self both diachronically and synchronically, places a burden and seemingly impossible expectation on practitioners. The narrative interpretation defended here makes two claims. First, capacity assessment can be considered as a mimetic activity and second, capacity assessment is a site of identity negotiation. This challenges the notion that capacity assessment is strictly about the individual assessed but calls for recognition of the social context and identity of the assessor and questions the idea that capacity is a claim about an individual. This narrative reading of mental capacity, comprised of mimetic and identity negotiation claims, challenges the coherence of the MCA's cognitivist approach. The practice of conferring capacity or incapacity is not defended or critiqued here, rather a narrative approach is proposed as providing a more accurate description of practices in capacity assessment. In highlighting the inadequacies of the MCA's approach, a narrative approach problematizes the instigation of capacity assessment, the nature of what is assessed and the conception that capacity is time-specific. Although this approach adds a complexity to understanding the assessment process, it identifies practical and conceptual difficulties and as such provides a more coherent account of practice.

In Part II a narrative approach to selfhood is developed from a reading of Paul Ricoeur and linked to the work of Marya Schechtman and Hilde Lindemann. Part III begins with a brief overview of difficulties in the application of the MCA. In Part III.1 four ways in which narrative identity can be applied to mental capacity practice are identified. In section III.2 a mimetic account of assessment is developed. The challenges such an approach poses to the functional model of the MCA are outlined in III.3. In Part IV the second claim of the narrative approach is proposed, namely that mental capacity assessment involves identity negotiation for at least two people. Finally, in Part V the narrative identity theory of mental capacity is set out and its relation to the functional model of capacity developed.

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[10] Paul Ricoeur's understanding of narrative identity is developed across multiple works. See P Ricoeur, *Time and Narrative* Vol. I, II, III, (K Mclaughlin and Pellauer tr, University of Chicago Press, Chicago 1984, 1985, 1988) & P Ricoeur, *Oneself as Another*, (K Blamey tr, University of Chicago Press, Chicago 1992).

[11] P Ricoeur, 'Life in Quest of Narrative' in D Wood (eds), *On Paul Ricoeur: Narrative and Interpretation*, (Routledge, London: 1991).

II. NARRATIVE SELFHOOD

The opportunity to understand the self and selfhood outside of a liberal conception of the self is offered by vulnerability[12] and relational approaches.[13] In drawing attention to the role of others and context, purely internal approaches to understanding the self are challenged. Paul Ricoeur's understanding of narrative identity echoes this concern with how the self is viewed and can be read as offering an alternative to internal accounts of the self. A reading of Ricoeur's understanding of narrative leaves some ambiguity as to how narrative identity is negotiated. Schechtman's conception of narrative self-constitution and Lindemann's account of the relational practice of identity negotiation it is proposed here complement Ricoeur's understanding and provide additional support for the application of a narrative approach to mental capacity. In Part III, mental capacity assessment is considered through the lens of narrative identity.

In *Time and Narrative (TN)* Ricoeur develops his most detailed account of the function of narrative and crucially the mechanics of narrative practice. The practice of narrative, whether fictive, historical or personal, has as its theme time or the "temporal character of human experience".[14] It is the mediating function of narrative that allows temporality to be accessible to consideration. The activity of narrative attempts to but does not resolve the "paradoxical nature of time".[15] The first problem is the conflict between phenomenological and cosmological time, or between lived and objective time. The second problem is the dissociation or distention caused by the past, present and future in awareness that "the future is not yet, the past is no longer, and the present does not remain".[16] The third problem is the 'inscrutability' of time, that for all the efforts of narrative, time evades constitution. In Ricoeur's later works on narrative, the focus is on the primacy of narrative identity for lived experience, the function narrative identity plays in synthesizing two aspects of selfhood and an understanding of the relation between selfhood, narrative and narrative identity.

In Book One of *TN,* Ricoeur introduces his threefold understanding of mimesis as the process through which time becomes refigured and productive. Whereas the action of telling a story is often associated with narrative, Ricoeur develops a broader approach. *Mimesis*$_1$, as the first stage of narrative corresponds to the preconditions for any act of narrative emplotment. Before an individual can narrate their identity there must be in play a "pre-understanding of the world of action", comprised of structural, symbolic and temporal dimensions.[17] An individual must be versed in the "conceptual network" through which action can be talked about, understand that action is symbolically

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[12] See F Luna, *Bioethics and Vulnerability: A Latin American View* (Rodopi, New York 2006) and C Mackenzie, W Rogers and S Dodds, (2014) *Vulnerability: New Essays in Ethics and Feminist Philosophy*, (Oxford University Press, New York 2014).

[13] See C Kong, *Mental Capacity in Relationship: Decision-Making, Dialogue and Autonomy* (Cambridge University Press, Cambridge 2017); B Clough, 'Vulnerability and Capacity to Consent to Sex- Asking the Right Questions?' (2015) 26(4) Child and Family Law Quarterly, 371-397; C Mackenzie and N Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self,* (Oxford University Press, New York 2000).

[14] P Ricoeur, *Time and Narrative* Vol. I (K Mclaughlin and Pellauer tr, University of Chicago Press, Chicago 1984), 3.

[15] D Wood, 'Introduction: Interpreting Narrative' in D Wood (eds), *On Paul Ricoeur: Narrative and Interpretation*, (Routledge, London: 1991) 1.

[16] Ricoeur, above, n 14, 7.

[17] ibid, 54.

articulated and appreciate the temporal aspects of experience which are considered to require a narrative response.[18] *Mimesis*$_2$ refers to the stage of emplotting an account of action and serves to synthesise events and occurrences and impose a configurational order on to events. As a cultural practice, narrating is governed by a tradition of available schemas through which one can create a narrative account. Finally, *Mimesis*$_3$ refers to the final stage where the proposed narrative is brought to the world. It is only at this stage of "application", that narratives become complete.[19] At this stage the text or narrative of the author intersects with the "world of the hearer or reader".[20] The narrative proposed projects a particular horizon or understanding of the world.

Ricoeur's later discussions of narrative identity can be read as complementary to the exposition of the mimetic function and its relation to time. In 'Life in Quest of Narrative', narratives are considered to address three relations; man's relationship with the world, others and himself.[21] Narrative identity corresponds to the third and as such is self-understanding. It is in the activity of interpreting one's experiences through narrative that human existence becomes lived. Life becomes meaningful and life itself through the activity of telling stories about it. Although narrative identity relates to self-understanding, Ricoeur is not suggesting that it is a distinctly first personal or private activity.

In two chapters of *Oneself as Another* Ricoeur advances an understanding of narrative identity as a response to difficulties in personal identity debates. Ricoeur proposes two poles of identity: "identity as sameness (idem)" and "identity as selfhood (ipse)".[22] The traditional approach to personal identity seeks to look for that which provides continuity through time or that which remains the same and allows for identity over time to be observed. The focus on identity as sameness at the expense of selfhood fails to appreciate the activities persons alongside others engage in to negotiate and maintain identities. Identity as selfhood corresponds to two aspects which allow for persons to persist through time. Selfhood as character refers to "the set of lasting dispositions by which a person is recognized".[23] Selfhood as 'keeping one's word' designates the activity of self constancy in the face of change. It refers to the who of identity. Between these two, the sameness of character by which individuals are recognised and the selfhood of keeping one's word lies an interval in which narrative identity operates. It serves to unify both the way in which the self and others view the self as having a character, and the activities of selfhood through time.

In telling stories or offering narratives, individuals plot accounts that involve the identity of characters including their own character. Narrative provides a space where individuals talk about their character in the midst of action. In talking about one's own character alongside events and other characters, the narrator imposes an imaginative account which seeks to bring a unity or coherence to their life. The activity of narrative identity acts to blur the lines between "author, narrator and character" and at times

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[18] ibid, 55.
[19] ibid, 70.
[20] ibid, 71.
[21] Ricoeur, above, n 11, 27.
[22] Ricoeur,1992, above, n 10, 116.
[23] ibid, 121.

one is all three.[24] However, as the ability to narrate is governed by tradition and the culture one inhabits offers ways of narrating, Ricoeur argues that at best one should be considered a co-author of their own narratives.

Narrative selfhood refers then to the narrative activity that selves are involved in as they seek self-understanding through the interpretation of experience and in doing so draw together identity as selfhood and sameness. Although Ricoeur fails to address the mimetic component of personal identity in his later writing it is evident from Part IV of *TN* that he intended narrative identity (both community and personal) to be read through a mimetic lens. In Part III of *TN* Ricoeur claims that fictional and historical narratives are preceded by a use of narrative in daily life. As co-authors, individuals are not just engaged by narrative selfhood in their own self-understanding but act as members of the culture that offer available narratives to others and provide critical readership of other's narrative accounts. This approach to narrative selfhood allows for a distinction between individuals, narratives and narrative identities. Individuals exist within cultures with traditions of understanding and ways to make sense of personal experience. Alongside others, individuals tell stories or offer narrative accounts which project particular interpretations of their own character, their world and relationships for readership. However, others are implicated in this process as both those who offer narrative schemas but also those who read their narratives. Furthermore, individual's narratives must include not just their own selfhood but also their sameness, which involves both how others and they see and identify themselves. Narrative identity refers to that which acts to bring together the two poles of one's identity and can be considered to include varying narratives which are continually being negotiated. The practice of narrative selfhood can be considered self-constituting, as it is through this activity that an attempt to make sense of one's self is performed, which can then go on to inform how both the individual and others understand the individual.

Although a critical examination of Ricoeur's account is not the aim of this paper, it is important to acknowledge that debates concerning the role of narrative as it relates to the self are common.[25] Ricoeur's work can be considered alongside others as calling for the primacy of narrative in understanding the self which itself is subject to sustained debate in philosophy and the medical humanities. Bringing the discussion back to personal narrative identity, further questions remain. At what point might it be appropriate to say an individual is engaged in narrative identity or narrative selfhood? This work proposes that the practice of mental capacity assessment can be understood through the language of mimesis and more generally as an activity of mimesis$_3$, the stage of critical readership. At the point of application, where the proposed narrative meets the world, the basis on which narratives are accepted or rejected requires clarification. It is proposed here that Marya Schechtman's *The Constitution of Selves* and Hilde Lindemann's *Holding and Letting Go* complement Ricoeur's understanding of the act of critical readership.[26] Three questions can be

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[24] ibid, 159.

[25] See J McCarthy, *Dennett and Ricoeur on the Narrative Self*, (Humanity Books, New York 2007), 230-231; G Strawson, 'Against Narrativity' (2004) 4 Ratio 428-452; A Woods, 'Post-narrative – An Appeal' (2011) 2 Narrative Inquiry 399-406.

[26] See M Schechtman, *The Constitution of Selves*, (Cornell University Press, Ithaca 1996) and H Lindemann, *Holding and Letting Go: The Social Practice of Personal Identity*, (Oxford University Press, New York 2014).

raised about this critical stage of readership. Who gets to perform critical readership of another's narratives and narrative identity? When do personal narratives and narrative identity receive critical readership? What are the criteria with which personal narratives and narrative identity are evaluated?

The act of mental capacity assessment it is argued here can be considered to engage with the first and second question. This is not to suggest that mental capacity assessment is the only site of critical readership or that assessors are the only persons permitted to assess narrative identity. Echoing Ricoeur, Schechtman proposes a narrative self-constitution view which affords central importance to others. While narrative self-conceptions can be considered personal, Schechtman observes that individuals must comply with "The Articulation Constraint" and "The Reality Constraint".[27] This suggests that narrative accounts at times are required to be articulated and where this is not provided there is scope for one's narrative identity to be questioned. A further constraint on the content of narratives is that they must comply with norms concerning narrative construction. Narratives must not violate clear facts about the world or be guilty of interpretive inaccuracies. Lindemann further complements this notion of identity being subject to critical readership in developing an account of the process of holding and letting go. Central to the development of identity, itself a process of personhood, is the importance of recognition by others. Lindemann argues that the performance of identity is itself a regulated behaviour wherein others can have four grounds on which identity can be denied. These are "malfunctioning mental states", "misleading expressions", "misfiring recognition" and "misshapen response".[28]

In the remainder of this paper, Ricoeur's notion of narrative identity, narrative selfhood, mimesis and identity negotiation are applied to the practice of mental capacity assessment. The approaches of Ricoeur, Schechtman and Lindemann offer a vocabulary which allows for a new description of what happens in mental capacity assessment.

III. CAPACITY ASSESSMENTS AND NARRATIVE IDENTITY

The uptake of a two-stage diagnostic and functional approach to assessing capacity in the MCA is drawn from the Law Commission's examination of different approaches to mental capacity.[29] The Act requires that for a person to be found to lack capacity they must be 'unable to make a decision for himself in relation to the matter because of an impairment, or a disturbance in the function of the mind or brain'. The inclusion of a diagnostic threshold serves to forbid the use of capacity legislation to interfere in the lives of those without a disability. The two-stage approach establishes the need for a causal nexus between the inability and the impairment to be identified for a finding of incapacity. The two-stage approach gives rise to two interpretations about the order in which assessment takes place. On one reading of Section 2(1), the functional ability to make a decision is the primary concern and when lacking it becomes appropriate to assess whether it is caused by an impairment. An alternative reading is to follow the structure of the Act whereby the diagnostic threshold is first considered (Section 2)

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[27] Schechtman, above, n 26, 114- 121.

[28] Lindemann, above, n 26, 106-117.

[29] Law Commission, *Mentally Incapacitated Adults and Decision-Making: A New Jurisdiction* (Law Com No 128, Consultation Paper No. 128, 1992), 22.

and when an impairment is present then an assessment of functional capacity (Section 3) is to be undertaken. The adoption of either approach to stages of capacity assessment however fails to clarify what triggers or instigates a capacity assessment. Unless all healthcare decisions are assessed through a diagnosis and then function approach or vice versa, then a justification for the initial decision to assess capacity in respect of some decision is required.

The functional model of capacity endorsed in the MCA constitutes decision making ability as composed of four abilities: understanding, retaining of information, use or weighing of information and communication. The first requirement holds that decision makers must have the ability to understand information relevant to the decision.[30] The second requirement that persons retain information introduces complexity in relation to duration in two regards. Firstly, where a person lacks the time to retain information or that ability is inconsistent, then the notion of fluctuating capacity is considered to arise. The second issue relates to the duration of decisions to be made and the relevance of retention of information if capacity is always decision specific.[31] Where a decision involves a duration such as where a person should live or whether to force feed a patient for a period of time, the role of retention of information concerns the decision making itself. The third requirement that persons use or weigh information expects decision makers not just to understand information but to be able to reflexively appropriate and endorse the decision.[32] The fourth component of communication is a residual requirement that speaks to situations where an individual is incapable of communication which prevents judgement on the other three abilities.[33] Although the decision maker is required to demonstrate the functional abilities, they are entitled to support in respect of each ability as the second guiding principle of the Act requires that “all practicable steps be taken to help the person in making the decision”.[34] These abilities correspond to the internal requirements the decision maker must demonstrate but the decision itself must be already identified as a matter which must be decided upon. Although this paper is unable to explore this question, the issue of the appropriateness of decisions put to persons seems central to discussion of capacity.

The implementation of the MCA, the move from theory to practice, can be considered both in regard to what practice is performed in its name but also what practice the MCA actually calls for. The application of the MCA is guided somewhat by the Code of Practice; however, it is non-binding. Critical discussions of the first four sections of the Act reveal several challenges facing would-be assessors of capacity. As noted by Mackenzie and Rogers, the Act appeals to a synchronic conception of capacity assessment as capacity is specific to a “material time”.[35] This notion of time however is challenged as the person is to be considered through time in respect of retaining information,[36] to be supported in making the decision with ‘all practicable steps”,[37] to be evaluated in relation to the likelihood of having capacity at a later time,[38] and to

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[30] Mental Capacity Act 2005, s 3(1)(a).
[31] Mental Capacity Act 2005, s 3(1)(b)
[32] Mental Capacity Act 2005, s 3(1)(c)
[33] Mental Capacity Act 2005, s 3(1)(d)
[34] Mental Capacity Act 2005, s 1(2).
[35] Mental Capacity Act 2005, s 2(1).
[36] Mental Capacity Act 2005, s 3(1)(b).
[37] Mental Capacity Act 2005, s 1(3).
[38] Mental Capacity Act 2005, s 4(3)(a)

have their past and present wishes considered in relation to best interests decision.[39] The feasibility of testing the four functional abilities in accordance with the MCA, which seemingly allows for a distinction between an incapacitous decision and a simply unwise decision, has received considerable scrutiny and outstanding questions remain as to how it is to be performed.[40] The expectation that the assessor of capacity act with a degree of objectivity and to avoid preconceptions suggests either an unwillingness to acknowledge that capacity assessments might reflect the assessor's values or that the person doing the judging is without perspective.[41] At a more general level, the concern has been raised that "inherent tensions" exist between the MCA in law and theory and the assessment of capacity in practice.[42] Manthorpe et al argue that for this tension to be overcome a more nuanced understanding of the Act to guide practice is required.[43] A common feature of the difficulties confronting the implementation of the Act rather obviously is the role of the assessor. Difficulties in relation to how to see the patient, evaluate mental processes, act without bias and begin the capacity assessment need to be addressed if capacity assessment is to coherently enact the MCA.

III.1 Situating Narrative Identity

The adoption of a functional and diagnostic approach to capacity, coupled with insufficient guidance for the assessor, may be seen to leave little scope for applying a narrative identity approach to capacity assessment. Arguably the subjectivity or perspective of the assessor is avoided. The adoption of relational approaches to mental capacity in recent years, alongside the UNCRPD and associated claims for a social model of disability, challenge the traditional liberal conception of the self. The different uses of narrative identity in theorising mental capacity assessment offer both complementary and critical perspectives on the liberal/functional approach adopted in the MCA.

In the first approach, narrative identity can be considered a resource for assessors of capacity as they seek to identify the wills and preferences of a person found to lack capacity. As Jeffrey Blustein notes, a "continuer view" can understand the role of others as extending the individual's narrative identity where the individual's ability to do so is lacking.[44] For example, where a person is diagnosed with advanced dementia

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[39] Mental Capacity Act 2005, s 4(6)(a-b)

[40] J Craigie, 'Competence, Practical Rationality and what a patient values' (2011) 25(6) Bioethics and T Thornton, 'Capacity, Mental Mechanisms and Unwise Decisions', (2011) 18(2) Philosophy, Psychiatry and Psychology 127-132.

[41] See M Donnelly, 'Capacity Assessment under the Mental Capacity Act 2005: Delivering on the Functional Approach?' (2009) 29(3) Legal Studies 464-491; D Gibson, 'Conceptual and Ethical Problems in the Mental Capacity Act 2005: An Interrogation of the Assessment Process' (2015) 4 Laws 229-244; M Minow, Making All the Difference: Inclusion, Exclusion and American Law, (Cornell University Press, New York 1990), 51; S Stefan, 'Silencing the Different Voice: Competence, Feminist Theory, and Law' (1993) 47 University of Miami Law Review 763-815, 780.

[42] K Hinsliff-Smith, R Feakes, G Whitworth, J Seymour, N Moghaddam, T Dening & K Fox 'What we know about the application of the Mental Capacity Act (2005) in healthcare practice regarding decision-making for frail and older people? A systematic literature review' (2017) 2 Health and Social Care in the Community 295-308, 306.

[43] J Manthorpe, K Samsi, H Heath & N Charles ''Early days': Knowledge and use of the Mental Capacity Act 2005 by care home managers and staff' (2011) 3 Dementia 283-298.

[44] J Blustein, 'Choosing for Others as Continuing a Life Story: The Problem of Personal Identity Revisited', (1999) 27 Journal of Law, Medicine and Ethics, 20.

and found to lack capacity about where to live, the person's narrative identity could be viewed as limiting of potential choices, such that whatever choice is made is consistent with the person's wishes as previously expressed. While this approach may be intuitively appealing for those seeking to honour a person's narrative identity, a range of issues need to be clarified, including the issue of whether wills and preferences or an individual's life narrative should have priority, how an individual's narrative is to be discerned, that is if there is only one, how to deal with conflicting narratives and finally how to choose between actions which all are consistent with an individual's narrative identity.[45] This narrative approach however does complement contemporary attempts to distinguish between mental capacity and legal capacity.[46] An appreciation of a person's narrative identity in cases of mental incapacity allows for their legal capacity to be preserved as it is their values and identity guiding decision making.

A second approach is to view the capacity assessment process as the production of a narrative identity account, whereby the assessor is engaged in the co-construction of a patient's narrative identity. Research drawing on this approach could seek to examine conventions and traditions informing how a patient's narrative identity are articulated but also examine the reading that capacity assessors perform of a patient's narratives. Carol Johnston and others draw attention to the role capacity assessors and judges play in determining what a patient's narrative involves, which can then influence best interest decisions.[47] This approach highlights how capacity assessors in asking certain questions and focusing on some issues over others, in effect, construct and/or limit the narrative identities of the person in question. The questions of assessors can be understood as having an editorial function.

A third approach, as set out by Michael Bach and Lana Kerzner, proposes that a definition of decision-making ability should include a narrative component.[48] In rejection of an individualist conception of selfhood, Bach and Kerzner argue that the assessment of decision-making ability should be based on whether an individual has the capacity to express their wills and intentions to others, who can then recognise and ascribe agency to the individual's actions, and secondly, the individual's ability to answer who they are, articulate a life story, and for that narrative account, to "direct the decisions that give effect" to a person's intentions.[49] Here, the adoption of a relational approach to agency and selfhood recognises narrative identity as central to deciphering decision making ability or its lack, crucially though by locating the ability within an individual's interaction with their community. Therein inability to make decisions is a feature of the individual and community, not the individual's mind or brain.

A fourth approach can view the capacity assessment process as a narrative practice in its own right. Therein it understands that the object of a capacity assessment is a

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[45] M Kuczewski, 'Narrative Views of Personal Identity and Substituted Judgement in Surrogate Decision Making', (1999) 27 Journal of Law, Medicine & Ethics, 34-35.

[46] UNCRPD Article 12(2). For further discussion of legal capacity see A Dhanda, 'Legal Capacity in the Disability Rights Convention: Stranglehold for the Past or Lodestar for the Future?' (2007) 34 Syracuse Journal of International Law & Commerce 429.

[47] C Johnston, N Banner and A Fenwick, 'Patient narrative: an 'on-switch' for evaluating best interests', (2016) 38(3) Journal of Social Welfare and Family Law, 249-262.

[48] M Bach and L Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' Report to the Law Commission of Ontario, 2010.

[49] ibid, 65.

person's narrative or their narrative identity, that the determination of best interests or a substituted judgement can seek to continue an individual's engagement in narrative identity, and that the resultant judgement is an act of co-authoring of a narrative identity. Furthermore, capacity assessment practices are made possible by narrative identity and narrative selfhood and such practices are in fact a stage of critical readership of the individual. This work now turns to developing the fourth approach, where capacity assessment is understood as a distinctly narrative practice comprised of mimetic (Part III.2) and an identity negotiation (Part IV) dimension.

III.2 A Mimetic Account of Mental Capacity Assessment

The practice of capacity assessment can initially be read as corresponding to *mimesis*$_3$, the stage of application, where a narrative is subjected to critical readership. A person's decision or lack of a decision is read by the assessor of capacity and the action either rejected or accepted. This account of assessment as critical reading allows for four mimetic stages or periods of capacity assessment to be identified.

Prior to any capacity assessment taking place however, there must already be two accepted narratives operative in the context. First, the assessor must have accepted and understood that the MCA is an appropriate symbolic, structural and temporal resource for categorising human action and secondly, there must be an accepted narrative which holds that a decision must be made. The presence of these two resources, however, is insufficient to account for the commencement of a capacity assessment. The origin of any capacity assessment can be seen to emerge because of the narrative context, of which there are three types. Where an individual's own account of what action is to be taken is the only proffered narrative, a capacity assessment will not be triggered. Where there is no account offered by the individual, as in cases of an unconscious patient, there is a *narrative deficit*. In such cases, there is an absence of a perspective to guide action and so a capacity assessment can be triggered. The third situation arises where in addition to a patient's proposed account, there are also other accounts proposed, resulting in *narrative conflict*. Only where the alternative narrative is considered to have weight or relevance does *narrative conflict* precipitate an assessment. The instigation of a capacity assessment in cases, save in cases of *narrative deficit*, is contingent on the possessor of the alternative account of action believing that it should be relevant and in doing so questions the authority of the patient's account. An example of narrative conflict would be if a patient maintains that she is unwilling to have life-saving heart surgery and yet her nurse's narrative includes the patient's commitment to being at her own daughter's wedding in five years.

The second stage of the process begins when, in the presence of *narrative deficit* or *narrative conflict*, the response of the assessor takes the form of a proposal of an alternative narrative, one which holds that the patient lacks capacity in respect of a decision. The acceptance of this incapacity narrative is dependent on the evaluation of the patient's original account about the decision. In cases of *narrative deficit*, this activity often goes unnoticed, as the patient is found to not be able to communicate a decision, and by default the incapacity narrative is accepted. In cases of *narrative conflict* however, the patient's engagement with the decision to be made is evaluated. The MCA requires that the basis on which someone can fail in this respect is where 'impairment of, or disturbance in the functioning of, the mind or brain' contributes to an inability to perform one or more of the tasks of understanding, retention, weighing and communication (URWC). A mimetic account allows for a reinterpretation of what is being assessed under the label of URWC as whether an individual's narrative account demonstrates congruence with established narrative conventions and as such avoids an "error of fact" or "interpretive inaccuracies".[50] Where an individual is found to have performed URWC (a cognitivist approach) or avoided 'errors of fact' or 'interpretive inaccuracies' (a mimetic approach), then their narrative account will be accepted and the proposed incapacity narrative will be rejected. Where an individual is found to have failed to perform URWC (a cognitivist approach) or demonstrated 'errors of fact' or 'interpretive inaccuracies' (a mimetic approach) then the proposed incapacity narrative will be endorsed.

The third stage of the mimetic process commences after the endorsement of the incapacity narrative. This in turn beckons in the issue of what narrative account is to be supported in place of either the discredited narrative, or in cases of *narrative deficit*, an absent one. Assessors are thus confronted with the challenge of how to negotiate "substituted decision-making", of which best interests and wills and preferences are available guiding principles.[51] In such cases the assessor can legitimately be considered a co-author of the individual whose decisions are being considered, as they are charged with identifying which narrative account should guide the individual in the future. Alternatively the role of the assessor can be minimised and instead a 'continuer' approach be endorsed. Therein the person's narrative identity and/or wills and preferences guide the decision.

The fourth stage or final stage can be identified where the best interests or substituted decision has been endorsed. The activity of critically reading an individual's narrative is complete, and where the individual is found to lack capacity, an alternative account endorsed. The conclusion of the activity of critically reading the individuals narrative results in the activity taking on the status of *mimesis*$_1$, as an established fact, which may have relevance in respect of future decisions.

The reading of the mental capacity assessment process as a mimetic activity calls for a more nuanced understanding of capacity assessment and accordingly affords central importance to the role of the assessor. The adoption of a mimetic understanding of capacity assessment allows for greater recognition of those performing the assessment. The language and rhetoric of the MCA maintain that what lies at the heart of any determination is something 'mental', clarified in the Act as relating to 'mind' or 'brain', which contributes to a view that incapacity is a feature of a person, a functional inability. A mimetic account however allows for mental capacity to be identified as a concept which grounds a practice of critical readership. To claim that mental capacity is a relational term that corresponds to the relation between people and neither the assessor or assessed discretely, is arguably irrelevant. All forms of assessment by one person of another can be viewed as being relational in general and furthermore are liable to a narrative evaluation. The claim can however be made that what makes mental capacity practice, whether strictly in accordance with the MCA or not, an essentially narrative and relational practice, is the identification of three distinctly narrative features. First, mental capacity assessment, in cases of *narrative*

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[50] Schechtman, above, n 26, 121-123 and Lindemann, above, n 26, 103-117.

[51] A Buchanan, and DW Brock, *Deciding for Others: the ethics of surrogate decision-making*, (Cambridge University Press, Cambridge 1990) 10.

conflict, has as its object the person's own decision and self-understanding which may become part of their narrative identity but crucially is a product of either the person's implicit or explicit understanding of themselves. Second, the assessment of the person's decision by the assessor is an act of critical readership, of the third stage of mimesis, in which the assessor is permitted to appraise the self-understanding of another. As acknowledged by both Ricoeur and Schechtman, narrative self-constitution is an innately social activity. Third, the capacity assessment process requires the proposal of a narrative of incapacity by an assessor to instigate the process in the first place. What differentiates mental capacity assessment from some others forms of assessment is principally that it takes as its object an individual's narrative selfhood, the performance of the assessment is an activity of narrative selfhood by the assessor, and the process requires an initial proffering of an alternative narrative for another. The continued use of the term mental capacity however poses a problem for theorists seeking to acknowledge the mimetic dimensions of capacity assessment. This problem echoes the challenge faced by relational theorists challenging the traditional conception of autonomy in philosophical and legal discourse.[52]

Practically, the mimetic reading invites consideration to turn to the initial period of concern leading to the commencement of a capacity assessment. Whereas the MCA in Sections 2-4 establishes a framework for assessing capacity and determining best interests in cases of incapacity, there is a failure to adequately explain when practitioners should assess capacity. This failure may stem from the historical context to which the MCA responds, in which it seeks to curtail or limit practices of interfering with and constraining the rights of persons. As such, the use of the MCA need not specify when the Act is to be applied, as there is a presumed set of persons to whom the Act relates. A further contributing factor to the failure to explain the impetus to doubt capacity can be traced to the limited space given to considering the role played by the assessor in the process. The mimetic interpretation invites readers to acknowledge that where neither an alternative narrative account nor an incapacity narrative is proposed, then an individual can never be found to lack capacity. As the MCA commits itself to a presumption of capacity, a decision on the part of an assessor is required before incapacity can be conferred. Accordingly, to adequately explain the assessment process, sufficient consideration needs to be given to the assessor's role in instigating an assessment.

The everyday use of the MCA places a considerable responsibility, albeit unacknowledged, on assessors to initiate the capacity assessment process. In one set of cases, those of *narrative deficit* (stage four of the functional model), the assessor is required to propose a narrative of incapacity. Although this activity is not of concern here, the issue of whether all cases of *narrative deficit* are responded to with capacity assessment is worthy of further research. In cases where an individual offers a narrative account of action, however, the issue of what provides the impetus for the assessor to doubt an individual's capacity and subsequently propose a narrative of incapacity is unclear. Not all individuals with an impairment of the mind or brain have their decisions subject to a capacity assessment. Assessors of capacity are thus tasked, in cases of people who have articulated their own narrative accounts or decisions, to recognise alternative narrative accounts of action but also recognise

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[52] Mackenzie and Stoljar, above, n 13, 4.

when in fact it is appropriate to privilege such an alternative account and thus trigger a capacity assessment. The failure within the MCA or Code of Practice to provide guidance on when alternative narratives are to be proposed might also stem from the historical context in which capacity assessment is considered to apply. An additional issue arising from this requirement to commence capacity assessment is the seeming expectation on the assessor to both know the person and be able to identify an alternative narrative relevant to that person, or to be familiar with appropriate alternative narratives to offer in certain cases or classes of people.

The theorising of capacity assessment as a mimetic process also offers an alternative account of one of the cornerstones of the MCA. In accordance with the cognitivist model adopted, a judgement of incapacity is never considered global, binding on all the actions of an individual. Rather, it corresponds to a specific decision or issue and accordingly allows for accounts of simultaneous determinations of capacity and incapacity regarding different issues. The adoption of this decision specific approach contrasts with historical practices that deprived individuals of any right to partake in decision making based on status, a global determination.[53] An alternative account of the move away from global determinations of incapacity is offered by a mimetic approach. As capacity assessments are cases of critical readership of an individual's action, the assessment of some decisions and not others can simply be indicative of an assessor's concern with some of an individual's decisions, not all of them. The scope of capacity determinations such as those involving psychiatric inpatient treatment for a duration, financial matters, living arrangements and the relationships one can engage in, suggest while specific decisions might be considered, those decisions can have whole life or global impacts. Furthermore, as capacity determinations have the potential to impact on how individuals are understood and treated by others going forward, the impact of any capacity assessment can be considered greater than the decision in question.

III.3 Narrative Incongruence and the Spectre of Paternalism

The mimetic reading of capacity assessment allows for an understanding of the assessor's role in conferring the status of incapacity to emerge. Whereas the MCA's approach understands the assessor's role as one of identifying incapacity by applying the two-stage test, a mimetic approach rejects the notion that incapacity necessarily involves an impairment of the mind or brain or a failure to perform a set of functional tasks. Lindemann's theory of the interpersonal practice of 'holding and letting go' complements Ricoeur's understanding of *mimesis* and provides a basis for mental capacity determinations to be considered from the perspective of the assessor.[54] Lindemann contends that personhood is conferred on an individual by others. Others, in having the power to recognise or reject aspects of one's identity on a series of grounds, are engaged in a process of holding and letting go. Thus, the ability to perform an identity is regulated through a social act of critical readership.

Lindemann sets out four grounds on which personhood is rejected. The first justification occurs in situations of "malfunctioning mental states", whereby the individual can be considered incapable of maintaining a credible understanding of self

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[53] The Law Commission, *Mental Incapacity* 1995 (Law Com no 231), para 3.3 – 3.4

[54] Lindemann, above, n 26.

due to a cognitive deficit.[55] This approach echoes the MCA's understanding of incapacity as having its root cause in a cognitive impairment. The second basis on which an account can be rejected is "misleading expression".[56] In such cases the individual violates established social norms or accepted understanding. One form of this is "errors of fact", whereby an individual is wrong about a socially accepted fact.[57] In proposing an understanding that is inaccurate, the individual demonstrates a failure to appreciate the world they inhabit. Here we can think of a person who maintains that the world is flat. Whereas some facts are seemingly non-negotiable, there are a range of beliefs about the world, such as religious convictions, where there is more flexibility. For example, a person's belief in the existence or non-existence of god would not be deemed an error of fact.

The second form of misleading expression occurs where an individual violates an "interpretive" norm.[58] In such cases the individual might have an appreciation of the facts but their interpretation of those facts is considered inappropriate or unjustified. Here we can think of an individual who maintains that they are invincible and immortal having survived a deadly train crash. Other forms of interpretive error can involve the concealing of, or failure to disclose, issues related to oneself. An example of this can be seen where a doctor refuses to endorse a patient's understanding of themselves as clumsy or prone to falls, on the suspicion that the patient has refused to disclose incidents of domestic violence. The idea of misleading expression poses a challenge to the model endorsed in the MCA, as it separates out the evaluation of a decision from a consideration of the functional abilities. The idea of misleading expression calls for contemplation of cases whereby an assessor might seek to classify the individual's decision as incapacitous, where in fact the deficit is in their interpretation or understanding of facts alone. In accordance with the MCA such instances would not be grounds for a finding of incapacity. In accordance with Principle 2, assessors are required to provide all reasonable efforts to support an individual's understanding and accordingly prevent a finding of incapacity on the basis of error of fact alone. Furthermore, Principle 3 prohibits the conferring of incapacity where there is an unwise decision, preventing a finding of incapacity based on interpretive inaccuracy alone.

The third basis on which identity can be denied, that of "misfiring recognition", occurs when there is a failing on the part of one person to recognise or acknowledge another.[59] Cases of non-recognition can be informed by an interpretive inaccuracy or error of fact, whereby they prevent an acknowledgement of an another's account or impose a particular account on the person. Practices of oppression can be considered failures to acknowledge the perspective of another, which result in a failure to accept or permit a person's identity. The MCA can be considered to prohibit 'misfiring recognition' from guiding a capacity determination as principle 1 (section 1) requires that all individuals are presumed to have capacity until demonstrated otherwise and subsequently puts in place a framework for justifying a determination of incapacity, which relies on a concept of 'malfunctioning mental states'.

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[55] ibid, 106.
[56] ibid, 106.
[57] Schechtman, above, n 26, 121
[58] ibid, 125
[59] Lindemann, above, n 26, 109.

The fourth form of identity denial, “misshapen response”, occurs when an oppressor refuses or denies a person of their very individuality and experience.[60] Crucially this form of response involves recognition on one level, whereby the person is recognised by a particular status, whether it is woman, child, slave, teenager, disabled or refugee. Recognition however here serves to identify what form of response is appropriate or permitted. The form of response fails to acknowledge the experience or situation of the person and uses a category to justify practices. Lindemann proposes that misshapen response can take multiple forms from atrocities of “torture, enslavement, and rape”, practices of “segregation, lack of access to decent employment or education” to personal beliefs and attitudes towards particular groups of people.[61] The MCA, as an alternative to a status based approach to capacity, shifts capacity assessment practice away from generalised responses based on the status of a person, to an approach that considers the person on a decision by decision basis.

The MCA recognises a difference between denying narrative accounts on grounds of ‘mental malfunctioning’, ‘misfiring expression and ‘narrative recognition’, permitting malfunctioning as the only basis for a finding of incapacity. The difficulty confronting the implementation of the MCA is whether this distinction is maintained. It is possible to imagine cases of misfiring expression where an individual fails in respect of URWC or commits an error of fact or interpretation, has an identified impairment of the mind or brain, but that the former is not caused by the latter. For example, a patient with a brain tumour (an impairment of brain) who refuses chemotherapy and is identified as failing the cognitive task of weighing up of information, might be found to lack capacity on the basis of the two-stage test. However, it may be the case that the brain tumour has no bearing on the decision which is in fact related to the witnessing of a loved one undergoing chemotherapy treatment and a wish not to experience something similar. To overcome such doubts, supporters of the MCA must demonstrate how an impairment of the mind or brain is directly linked to the task of URWC and how this causal nexus is to be observed.

A further concern could be raised as to whether individuals found to fail URWC, but as such lacking the diagnostic requirement for a finding of incapacity, are subsequently submitted to examination and assessment to find an ‘impairment’ which would allow for a finding of incapacity. The failure of supporters of the MCA to explain the relationship between mental activities of the mind and brain and subsequent decisions leaves open the possibility that determinations of ‘mental malfunctioning’ may in fact be ones of ‘misfiring expression’. A further difficulty might confront the MCA if the requirement for a cognitive impairment is removed and the basis for a finding of incapacity is simply the URWC test.[62] Here the difficulty would involve the ability to distinguish between cases of misleading expression or misfiring recognition. Even without any changes to the MCA, it is possible to imagine situations where judges, nurses, doctors or carers, in positions of power by virtue of being able to commence a capacity assessment, label their own errors of fact, interpretive inaccuracies and failure to accommodate and support individuals, as cases of ‘misfiring expression’, when in practice they are cases of ‘misfiring recognition’.

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[60] ibid, 115.

[61] ibid, 116.

[62] See the approach adopted in Ireland’s Assisted-Decision Making (Capacity) Act 2015.

One interpretation of the MCA holds that it responds to the fact that there is incapacitous and capacitous action and therein sets out means to distinguish between the two, which then recognises autonomous action, or calls for a substituted/supported decision making. An alternative approach could view the MCA as implicated in the act of categorising human action. Rather than being at a distance, it defines what is permissible action over others, and then labels this as soft paternalism. The MCA permits assessors to identify that a decision has to be made, question an individual's capacity, perform the assessment of capacity and make a determination of best interests. Rather than simply identify what is capacitous or incapacitous action, it defines it, albeit somewhat unclearly. If this secondary understanding is adopted, then we can view the MCA as not simply permitting soft paternalist practice, but also opening up the possibility of cases of hard paternalism in situations of malfunctioning mental states, misfiring expression or misfiring recognition. This is disguised in the Code of Practice as the distinction between capacity and incapacity is presented as a natural distinction, rather than a product of a liberal understanding of personhood.[63]

IV. NEGOTIATING RELATIONALITY

The activity of capacity assessment can also be considered in the context of the therapeutic relationship, specifically in regard to the ongoing identities of the individual and the assessors involved. The performance of a capacity assessment necessarily involves participants engaging in a form of identity negotiation, whereby questions of "who am I" and "what do I do" are considered.[64] Although the mimetic reading of capacity assessment reveals the limits of narrative identity for the individual being assessed, the activity can also be considered a site where the assessor's identity is itself negotiated. The result of a capacity assessment is not simply local and discrete to a particular event; rather the event can become pivotal for the individual and the assessor in how they make sense of their personal and/or professional identities. Where it is often recognised that capacity determinations are a site of balancing discourses of care and respect for autonomy, then a concern with how such determinations can impact on both individuals taking part seems justified.

In cases of *narrative conflict*, the requirement placed on individuals to give an account of one's actions, in having that account subject to scrutiny and experiencing the proposal of an incapacity narrative, demonstrates how the narrative identity of an individual can become subject to critical readership and limitation. Where an individual is found to lack capacity and an alternative narrative account is put forward to guide the decision in question, the capacity assessment process can be understood to establish *mimesis*$_1$ conditions for the future in three respects. In a most basic sense, a determination of incapacity establishes a fact about that patient. While a determination of capacity can be act specific, the act itself might be one that occurs over a lengthy period of time but also the fact of the determination can become a resource or feature of the individual's identity going forward and of those in the individual's life. Secondly, the determination of incapacity or capacity serves to establish guidelines around what are symbolically appropriate or inappropriate ways to talk about conditions, decisions, risk, as well as personal justifications and beliefs. Thirdly, in a determination of incapacity with a prescribed action or inaction, the

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[63] *Mental Capacity Act 2005: Code of Practice* (TSO, London 2007) 1.

[64] K Atkins, *Narrative Identity and Moral Agency: A Practical Perspective*, (Routledge, New York 2010) 1.

individual is provided with the decision which may or may not be incorporated into their own understanding but also into the understanding of those around them going forward. Although the MCA sets an understanding of capacity as local, it should be acknowledged that determinations, the understanding of the process and the action or inaction prescribed, could have considerable global influence over the individual assessed.

Turning to the assessor's experience of capacity assessment, the implications for their own life are considerable. The assessor, in providing an alternative account of action, in proposing an incapacity narrative, in assessing the individual's capacity and determining a best-interests decision, is expressing an understanding of their professional identity. These activities, specifically in cases that lead to *narrative conflict*, are not something they do, nor can do, in every interaction they have as professionals. The activity of capacity assessment can be seen to also establish *mimesis*$_1$ conditions for the assessor. The performance of the assessment, as well as the relative success of the proposed incapacity narrative, can establish symbolic resources for the assessor to guide future capacity assessments. Secondly, the assessment of an individual can become part of the assessor's own professional identity, a site whereby they can make sense of their professional responsibilities and reflect on the type of professional they are. Thirdly, a determination of incapacity can operate as a fact for the assessor in their understanding of the individual assessed going forward.

V. A NARRATIVE THEORY OF CAPACITY ASSESSMENT

In drawing on the mimetic and identity negotiating dimensions of mental capacity assessment, a narrative theory of capacity assessment can be formulated. Such a theory however, is not supportive or critical of the practice of mental capacity assessment; rather it is a descriptive account of capacity assessment. The aim therein of a narrative theory is not to attempt to justify the practice of classifying an individual as lacking in capacity, but to interrogate what is happening in capacity assessment. Although a mimetic reading is possible in cases of *narrative deficit*, the adoption of a narrative approach is here confined to situations in which the individual articulates a narrative account of action. The three principles of a narrative theory of capacity assessment are:

i) Mental Capacity determinations are judgements arising from and sometimes relating to an individual's personal identity but always in a relational dynamic.

ii) What is assessed in mental capacity determinations is the congruence between the narrative account of events or behaviours of the assessor and the assessed.

iii) The impetus to assess capacity begins where alternative accounts that can lead to *narrative conflict* are shared with or identified by an assessor of capacity. *

* Where capacity assessment is commenced at the request of a colleague or family member, the assessor may be considered not to instigate the process. Such an interpretation however is rejected. The mimetic precondition for capacity assessment is the acceptance of two narratives, the narrative of the MCA and the narrative that a decision needs to be made. Where the decision to commence a capacity assessment

is at the request of another, the person who makes the request can be considered through the lens of the first two mimetic stages set out above. The assessor who commences the assessment can be viewed as accepting the truth of *narrative conflict* or *narrative deficit* and the appropriate response of assessing capacity. The only difference from the original model is that the assessor here doesn't observe or encounter *narrative conflict* or *narrative deficit* before deciding to assess. In accepting the recommendation of another and acting upon it, they instigate the assessment process.

The interpretation of mental capacity assessment from a narrative approach to selfhood allowed for the identification of capacity assessment as comprised of a four-stage mimetic process and as a site of narrative identity negotiation. Together, a reading of capacity assessment as mimesis and the negotiation of narrative identity inform a narrative theory of mental capacity assessment. Critically, this theory does not seek to endorse or justify the practice of conferring incapacity on persons but rather proposes a descriptive account of the phenomenon of mental capacity assessment. Accordingly, a narrative theory is not a guide for mental capacity practice nor a call for particular practice. The narrative reading developed here reveals that the cognitivist approach insufficiently addresses the first stage of capacity assessment, leaving assessors unclear as to when their duties to doubt capacity emerge. Furthermore, the failure to clarify the relation between a cognitive impairment in the mind or brain and an inability to perform a task of UWRC raises questions about the basis on which capacity determinations are made, whether individuals are labelled as lacking in capacity based on simply holding an alternative understanding, and challenges the language of capacity assessment which views capacity as something intrinsic or discrete to an individual.

The narrative approach to selfhood developed here allows for mental capacity to be considered a relational term which is utilised in interactions in which people are sanctioned to offer alternative accounts of others' lives and actions. The question may be raised as to whether mental capacity and incapacity, as features or aspects of a broader processes of narrative selfhood, are in fact relationally constituted. The response however is not so simple. A narrative approach supports understanding determinations of mental incapacity as relationally constituted through a mimetic process. A narrative approach however does not deny that there can be impairments that underpin determinations of incapacity, but rather that a mechanism for distinguishing cases of mental malfunctioning from cases of misshapen response, misleading expression and misfiring recognition is lacking. Regardless of the basis for a determination of incapacity, the process is mimetic in nature. In regard to capacity, a narrative approach supports the claim that some aspects of capacity are relationally constituted. Where capacity requires the competencies to avoid committing errors of interpretation and factual errors, or violating the reality and articulation constraints, the acquisition of such competences can be identified as relationally constituted. The development of these skills emerges through the assistance of others, who through acts of critical reading, not just in relation to mental capacity assessment, but also less formally, guide individuals about acceptable ways of acting and developing self-understanding. The narrative approach however does not deny that such competencies are dependent on functioning mental states. The narrative approach to mental capacity proposed here both calls for mental capacity and incapacity to be acknowledged as relationally constituted while also acknowledging aspects of both are not so constituted. A narrative approach does not deny that individuals have and experience impairments. The narrative approach however challenges the confidence that mental capacity assessment is sufficiently developed to identify cases of mental malfunctioning and the claim that it simply evaluates decision making ability.

The appeal to narrative identity in theorising mental capacity, however, can vary from approaches which view narrative identity as something one has or that they express to those which view narrative identity as something performed and negotiated with others. As such, the appeal to narrative approaches in mental capacity discourse must be scrutinised as to whether it understands the individual in terms of what they have or are on the one hand, or whether it acknowledges the activity of individuals alongside others and the role narrative can play in this.[65] In *Re T (Adult: Refusal of Treatment)* (1992), Lord Donaldson stated that the capacity of a decision is not directly related to the "rational or irrational, unknown or even non-existent" reasons for making a choice.[66] A narrative approach alters this understanding slightly. Mental capacity is not related to whether a decision is rational or irrational, but rather about the perceived rationality of a decision as considered from the perspective of an individual sanctioned to question the decisions of others, who in this performance negotiates both the identity of the individual assessed, as well as their own.

A narrative approach to mental capacity assessment can be viewed then as both an alternative to but also complementary to the functional approach of the MCA. As an alternative, it challenges the inadequate consideration of the assessor's responsibilities in the assessment process, suggests that capacity assessment may focus on something other than functional ability and proposes that capacity assessment involves identity negotiation. Although more complex than the MCA's functional approach as it problematises the instigation of assessment, what is assessed and the notion that capacity assessment is decision specific, it highlights areas which need to be addressed if a 'wider' account of capacity assessment is to overcome tensions between theory and practice. In this latter sense, a narrative approach can be read as complementary as it identifies areas which need to be addressed within a functionalist approach to mental capacity.

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[65] The call to acknowledge the role of narrative identity work through stories is not supporting the claim that narrative is the only means through which identity is negotiated. See A Woods, 'Post-Narrative: An appeal', (2011) 21(2) Narrative Inquiry 399.

[66] *Re "T"* [1992] EWCA Civ 18, para 37.

SOME CONTINENTAL EUROPEAN PERSPECTIVES ON SAFEGUARDS IN THE CASE OF DEPRIVATION OF LIBERTY IN HEALTH AND SOCIAL CARE SETTINGS

WALTER BOENTE[*]

This article highlights perspectives and regulations on safeguards in the case of deprivation of liberty of some continental European countries – namely Germany, Switzerland, France, Austria, and Spain. It illustrates the continent's disparate approaches to the subject, both those founded in history and in the different legal traditions.[1]

Continental legislation struggles to cope with the UN Convention on the Rights of Persons with Disabilities. The most recent observations of the Committee on the Rights of Persons with Disabilities in Germany, in May 2015, recommend for example, that Germany "amend legislation to prohibit involuntary placement and promote alternative measures".[2] Nevertheless, legislation and practice in these countries might provide some different points of view on deprivation of liberty safeguards.

I. GERMANY

German law reflects the historically common structure of legislation concerning deprivation of liberty in health and social care settings on the continent. Provisions concerning deprivation of liberty grew on two grounds. On the one hand, regulation in private law, and thereby the promotion of the interest of the individual, led to provisions concerning deprivation of liberty in the health interests of the person concerned. On the other hand, regulation in public law, in particular administrative or rather public security law, led to provisions allowing deprivation of liberty to avert danger to life, health, or even "society"; in other words, for the protection of both the interests of individuals as well as the public. Because of these different legal approaches, one and the same interest could be "promoted" or "protected" by different provisions.[3]

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[*] Centre of Comparative, European and International Law, University of Lausanne. We thank Devrim Baki and Euan Elia Hindle for their generous support in the preparation of this article.

[1] For a comparison between the UK and for example Germany in this field, see H.R. Röttgers and P. Lepping, 'Treatment of the mentally ill in the Federal Republic of Germany: Sectioning practice, legal framework, medical practice and key differences between Germany and the UK', The Psychiatrist 23 (1999), pp. 601 et seq, even if outdated as a result of legislative developments.

[2] Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Germany, N 29 ff.; see also CPRD, Concluding observations on the initial report of Spain, N 35 f.; CRPD, Concluding observations on the initial report of Austria, N 30 ff.; full texts available at <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5> (last visited July 17, 2017).

[3] For (partially outdated) country reports on Germany in English see for example H.J. Salize, H. Dreßing, Country report on Germany, in: Salize, Dreßing, Peitz (eds.), 'Compulsory Admission and Involuntary Treatment of Mentally Ill Patients – Legislation and Practice in EU-Member States', 2002, pp. 82 et seq, full text available at <http://ec.europa.eu/health/ph_projects/2000/promotion/fp_promotion_2000_frep_08_en.pdf>; European Union Agency for Fundamental Rights (FRA), Country thematic reports on the fundamental rights of persons with intellectual disabilities and persons with mental health problems, Country report on Germany, full text available at <http://fra.europa.eu/sites/default/files/fra_uploads/2142-mental-health-study-2009-DE.pdf> (last visited July 17, 2017); see also E. Habermeyer, U. Rachvoll et al., 'Hospitalization and Civil Commitment of Individuals with Psychopathic Disorders in Germany, Russia

This historically established structure is still present in German law, not least because legislative power, in the case of private law, is in the hands of the federal government; in the case of public security law it is in the hands of the federal states, the Bundesländer. This concept also shines through the other continental legislation that will be addressed later.

A. Constitutional Law

In connection with deprivation of liberty in health and social care settings, the German system is, in contrast to other countries, not driven by the European Convention on Human Rights as such. Because of the crimes of the Third Reich,[4] the German Constitution, the so-called Basic law, stated as far back as 1949 that the liberty of the person can be *restricted* only pursuant to a formal law and that only a judge can rule upon the permissibility of any *deprivation* of liberty:

> **Art. 104 Basic Law for the Federal Republic of Germany.**
> (1) Liberty of the person may be restricted only pursuant to a formal law and only in compliance with the procedures prescribed therein. …
> (2) Only a judge may rule upon the permissibility or continuation of any deprivation of liberty. If such a deprivation is not based on a judicial order, a judicial decision shall be obtained without delay. …[5]

Therefore, the Basic law is still the starting point for German legislation and jurisprudence on deprivation of liberty.

B. Private law

German Private Law differentiates between "*accommodation* that is associated with deprivation of liberty" and other deprivations of liberty in institutions:

> **Section 1906 German Civil Code. Approval of the custodianship court with regard to accommodation.**
> (1) It is admissible for the custodian to put the person under custodianship in accommodation that is associated with deprivation of liberty only as long as this is necessary for the best interests of the person under custodianship because
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> > 1. by reason of a mental illness or mental or psychological handicap of the person under custodianship there is a danger that he will kill himself or cause substantial damage to his own health, or
> > 2. to avert the threat of substantial damage to health, an examination of the state of health of the person under custodianship, therapeutic treatment or an operation is necessary, which cannot be carried out without the accommodation of the person under custodianship and the person under custodianship, by reason of a mental illness or mental or psychological handicap, cannot recognise the necessity of the accommodation or cannot act in accordance with this realisation.
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> (2) The accommodation is admissible only with the approval of the custodianship court. Without the approval, the accommodation is admissible only if delay entails risk; the approval must thereafter be obtained without undue delay. …

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and the United States', in: Felthous, Saß (eds.), *The International Handbook of Psychopathic Disorders and the Law, Volume II, Law and Policies*, 2007, pp. 36 et seq.

[4] See R. Strous, 'Historical injustice in psychiatry with examples from Nazi Germany and others – ethical lessons for the modern professional', in: Kallert, Mezzich, Monahan (eds.), *Coercive Treatment in Psychiatry, Clinical, Legal and Ethical Aspects*, 2011, pp. 161 et seq; H.R. Röttgers/P. Lepping, n. 1 above, pp. 602 et seq.

[5] Full text in English available at <http://www.gesetze-im-internet.de/englisch_gg/> (last visited July 17, 2017).

> (4) Subsections (1) and (2) apply with the necessary modifications if the person under custodianship who is in an institution, a home or another establishment without being accommodated there is to be deprived of his liberty by mechanical devices, by medical drugs or in another way for a long period of time or regularly. …[6]

The condition for an *accommodation* associated with deprivation of liberty is that it is "necessary for the best interests of the person under custodianship". The following conditions embody the principle of legal certainty:[7] "by reason of a mental illness or mental or psychological handicap there is a danger that the person will kill himself or cause substantial damage to his own health", or "to avert the threat of substantial damage to health, an examination of the state of health of the person under custodianship, therapeutic treatment or an operation is necessary, which cannot be carried out without the accommodation of the person under custodianship and the person under custodianship, by reason of a mental illness or mental or psychological handicap, cannot recognise the necessity of the accommodation or cannot act in accordance with this realisation."[8]

Conditions for *other* deprivations of liberty in institutions – for example through "mechanical devices, by medical drugs or in another way for *a long period of time* or *regularly*" - are the same. The definition of "long period of time" is a controversial issue in court decisions and legal literature. In general, it depends on the method of the deprivation of liberty concerned. Against this background a period of several hours or at least one day is considered to be "long".[9] "Regularly" means a deprivation of liberty

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[6] Full text in English available at <http://www.gesetze-im-internet.de/englisch_bgb/> (last visited July 17, 2017).

[7] Cf. German Federal Constitutional Court (Bundesverfassungsgericht), 23. 3. 2011 − 2 BvR 882/09; German Federal Court of Justice (Bundesgerichtshof), 20.6.2012 - XII ZB 99/12 and XII ZB 130/12.

[8] For questions concerning coercive treatment see E. Flammer, T. Steinert, 'Involuntary medication, seclusion, and restraint in German psychiatric hospitals after the adoption of legislation in 2013', Frontiers in Psychiatry, 6:153, full text available at <http://journal.frontiersin.org/article/10.3389/fpsyt.2015.00153/full>; in comparison to the Netherlands T. Steinert, E.O. Noorthoorn, C.L. Mulder, The use of coercive interventions in mental health care in Germany and the Netherlands. A comparison of the developments in two neighbouring countries', Frontiers in Public Health 2:141, full text available at <http://journal.frontiersin.org/article/10.3389/fpubh.2014.00141/full>; in the light of the CRPD Staatliche Koordinierungsstelle, 'Position paper by the State Coordination Agency established in accordance with article 33 of the CRPD', full text available at <http://www.wcag2016.de/fileadmin/Mediendatenbank_WCAG/Tagungsmaterialien/Panels/Panel_08_position_paper_Forced_hospitalization_20130718.pdf>; lately the German Federal Constitutional Court (Bundesverfassungsgericht) declared the related provisions to be partly unconstitutional, full text in English available at <http://www.bundesverfassungsgericht.de/SharedDocs/Pressemitteilungen/EN/2016/bvg16-059.html> (last visited July 17, 2017); for a comment on this decision in English see A. Ward, A major step forward in CRPD compliance by the German Federal Constitutional Court?, < http://www.lexology.com/library/detail.aspx?g=7fdc889d-f50b-4d59-b84a-3bdb4bb75a51> (last visited July 17, 2017); for the ongoing reform process see <http://dipbt.bundestag.de/dip21/brd/2017/0066-17.pdf> and most recently < http://dipbt.bundestag.de/dip21/brd/2017/0512-17B.pdf>, only available in German (last visited July 17, 2017).

[9] For cases of deprivation of liberty due to the medical treatment itself Section 1904 CC applies: "Section 1904 German Civil Code. Approval of the custodianship court in the case of medical treatment. (1) The consent of the custodian to an examination of the state of health of the person under custodianship, to therapeutic treatment or to an operation is subject to the approval of the custodianship court if the justified danger exists that the person under custodianship will die or will suffer serious injury to his health that lasts for a long period by reason of the measure. Without the approval, the measure may be carried out only if delay entails danger.

repeated at the same time of the day or for the same reason, generally irrespective of its duration. Nevertheless regarding a time-threshold to establish deprivation of liberty, jurisprudence is in a state of flux, but considers at least thirty minutes as a deprivation of liberty.[10]

The competent authority or, figuratively speaking, (safe-)“guard” in these cases is the custodian who decides on the deprivation of liberty. In emergency cases, in particular if a custodian has not yet been appointed, the family court can take the necessary measures (Section 1846 CC).

The safeguarding process requires the mandatory approval of the custodianship court. If delay entails risk, the approval must be obtained without undue delay. This design of the safeguarding process involves a huge number of cases that have to be handled by the courts. In 2015, custodianship courts approved more than 120,000 cases of deprivation of liberty under Section 1906 CC.[11]

Some elements of the courts’ (safeguarding) process, as outlined in the Act on Proceedings in Family Matters and in Matters of Noncontentious Jurisdiction (APFNJ), are:[12]

- the appointment of a guardian ad litem for the person concerned (Section 317 APFNJ);

- an in-person hearing prior to the measure – to the extent necessary, in the usual environment of the person (Section 319 APFNJ);

- prior to an “*accommodation* that is associated with deprivation of liberty”, an expert opinion on the necessity of the measure has to be obtained. The expert should be a psychiatrist. He or she shall be a physician with experience in the field of psychiatry (Section 321 subsection 1 APFNJ). On the contrary for *other* deprivations of liberty in institutions, a medical certificate shall be sufficient (Section 321 subsection 2 APFNJ);

- duration and extension of the measure are covered by special provisions (Section 329 APFNJ): the involuntary commitment shall cease at the latest at the end of one year; in the case of an obvious need for a longer period of involuntary commitment at the latest at the end of two years, when it was not previously extended;

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(2) The non-consent to or revocation of the consent of the custodian to a test of the state of health, treatment or medical intervention requires the approval of the custodianship court if the measure is medically indicated and there is justified reason to fear that the person under custodianship will die or suffer serious, long-term detriment to health if the measure is not carried out or is discontinued.
(3) Approval pursuant to subsections (1) and (2) must be given if the consent, non-consent or revocation of consent corresponds to the will of the person under custodianship.
(4) Approval pursuant to subsections (1) and (2) is not required if agreement is reached between the custodian and the physician in attendance that the granting, non-granting or revocation of consent corresponds to the will of the person under custodianship established pursuant to section 1901a.
(5) Subsections (1) to (4) also apply to an authorised representative. The latter may only consent to, not consent to or revoke consent to one of the measures designated in subsection (1) sentence 1 or subsection (2) if the power of attorney expressly includes these measures and is given in writing.”

[10] See German Federal Court of Justice (Bundesgerichtshof), 7.1.2015 - XII ZB 395/14.

[11] The numbers of cases of deprivation of liberty under Section 1906 *subsection 4* CC currently decline; for statistics see <https://www.bundesjustizamt.de/DE/SharedDocs/Publikationen/Justizstatistik/Betreuungsverfahren.html> (last visited July 17, 2017).

[12] Full text in English available at <http://www.gesetze-im-internet.de/englisch_famfg/> (last visited July 17, 2017).

- finally, to make the measure public, special information duties apply (e.g. Section 339 APFNJ).

There are also two fast track procedures for the safeguarding process, with exceptions relating to the hearing of the person concerned as well as the prior appointment of the guardian ad litem (Sections 331, 332 APFNJ). The interlocutory order in turn shall not exceed a duration of six weeks (Section 333 subsection 1 sentence 1 APFNJ).

C. Public Security Law

Due to the distribution of legislative power in Germany, each German federal state has its own law on deprivation of liberty in health and care settings – which is a total of sixteen different laws. Although differing considerably in some of the detail, their overall approach is similar. Most of the laws developed from a pure public security law approach focused on averting danger but evolved over time to the mental health law approach today.

Therefore, deprivation of liberty in health and social care settings is also possible on the basis of federal state law, for example, for North Rhine-Westphalia, the Law on Assistance and Protective Measures in Cases of Mental Illness.[13]

Conditions of deprivation of liberty in German public law do not differ much from private law; differences derive from the scope and perspective of the protected interests. But while private law (the Civil Code) refers quite generally to the principle of proportionality, federal state law explicitly regulates the less invasive measures, including community care by multi-disciplinary teams or social psychiatric services. Furthermore, and different from private law, the execution of the deprivation of liberty is regulated more elaborately.

The competent authority or “guard” in these cases is the judge, while in emergency situations it is the local administrative authority, particularly the local health authority.

Today the courts’ safeguarding procedure is regulated by almost the same provisions as those enshrined in private law (see Section 312 no. 3 APFNJ). Furthermore, this safeguarding process is supported by additional information duties and administrative commissions visiting and supervising the institutions regularly.

D. Practice

For a long time there was a competence conflict between deprivation of liberty on the grounds of private law and public security law. In practice, the easiest way was often used. Today the safeguarding provisions are nearly the same, although fast track procedures are still a problem. However, because the competent person often remains the same and only the procedure changes, there is little motivation to use the fast track procedure as the work reverts to the same desk afterwards.

Today, discussions in this field are centred on the qualification of each person involved in the safeguarding process. There are also special research projects focusing in

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[13] For other examples see E. Habermeyer, U. Rachvoll et al., n. 3 above, pp. 37 et seq.

particular on the avoidance of restrictions of liberty and on awareness raising for less interfering alternatives.[14]

The UN Convention on the Rights of Persons with Disabilities is also an issue in Germany, but the focus lies on its practical rather than on its legislative implementation.[15]

II. SWITZERLAND

The last amendment of the Swiss provisions concerning deprivation of liberty was in 2013, when the so-called "centennial reform" of the law of protection of adults came into force.[16] While there is still an overlap of the regulations on deprivation of liberty in private and public law in Germany, in Switzerland there is today a clearer distinction between deprivation of liberty on the grounds of private law in the person's own interest, and deprivation of liberty through public security law in the interest of others.

A. ECHR

In contrast to the German system, the Swiss system is driven by the European Convention on Human Rights, not least because the Swiss Federal Supreme Court is not allowed to examine Swiss Federal Law, that is the law of the Federation itself.[17] A constitutional court in the proper sense does not exist.[18] This is why judgments of the European Court of Human Rights on Swiss Federal Law have a special impact on Swiss Legislation.[19]

B. Care-Related Hospitalisation

Swiss private law allows for the commitment to an appropriate institution. The conditions of hospitalisation are, in this case, that the person suffers from a mental disorder, or mental disability, or serious neglect and the required treatment or care cannot be provided otherwise:

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[14] See examples on the projects "ReduFix" and "Werdenfelser Weg" in the Statement of the German Federal Government regarding the three concluding observations made in paragraph 20, which were adopted in the framework of the presentation of the sixth periodic report of Germany (CCPR/C/DEU/6) by the Human Rights Committee on 30 and 31 October 2012 (2944th and 2945th meetings), pp. 6 et seq, full text in English available at <http://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/PDF-Dateien/Pakte_Konventionen/ICCPR/iccpr_state_report_germany_6_2010_cobs__2012_Follow_up_2013_BR_en.pdf> (last visited July 17, 2017); for the declining numbers of cases of deprivation of liberty under Section 1906 subsection 4 CC, see n. 11 above.

[15] See E. Flammer, T. Steinert, n. 8 above, pp. 1 seq.; with a focus on Art. 12 CRPD; V. Lipp, 'Guardianship and Autonomy: Foes or Friends?', in: Arai, Becker, Lipp (eds.), *Adult Guardianship Law for the 21st Century, Proceedings of the First World Congress on Adult Guardianship Law 2010*, 2013, pp. 103 et seq.

[16] See on this topic I. Schwenzer/T. Keller, 'A new law for the protection of adults', The International Survey of Family Law, 2013, pp. 375 et seq.

[17] See Art. 190 Federal Constitution of the Swiss Confederation: "The Federal Supreme Court and the other judicial authorities apply the federal acts and international law"; full text in English available at < https://www.admin.ch/opc/en/classified-compilation/19995395/index.html> (last visited July 17, 2017).

[18] On this topic T. Fleiner/A. Misic/N. Töpperwien, Constitutional Law in Switzerland, 2012, N. 663 et seq.

[19] See on this point T. Fleiner/A. Misic/N. Töpperwien, n. 18 above, N. 665.

> **Art. 426 Swiss Civil Code [Hospitalisation for treatment or care].**
> (1) A person suffering from a mental disorder or mental disability or serious neglect (the patient) may be committed to an appropriate institution if the required treatment or care cannot be provided otherwise.
> (2) The burden that the patient places on family members and third parties and their protection must be taken into account. …[20]

1. Adult protection authority

The competent authority or "guard" for care-related hospitalisation is generally the adult protection authority (Art. 428 para. 1 CC), but the detailed implementation of this competence set out under Swiss Federal Law is up to the Swiss cantons. As a consequence, the competent authority differs from canton to canton and is either an administrative authority or, especially in the French speaking cantons, a court.[21]

The procedure reflects some of the commonly known safeguards. If necessary, the adult protection authority shall order that the person is represented and appoint a person experienced in care-related and legal matters as his or her deputy (Art. 449a CC). The person shall be heard in person unless to do so appears inappropriate (Art. 447 para. 1 CC). If necessary, the adult protection authority shall commission an opinion from an expert (Art. 446 para. 3 CC). A review shall be conducted at the latest six months after hospitalisation, and a second review within the following six months; thereafter as often as necessary, but at least once every year (Art. 431 CC).

In addition, any person committed to an institution may appoint a person whom he or she trusts as a representative to support him or her during his stay and until the conclusion of all related procedures (Art. 432 CC).

2. Doctors

Furthermore, the cantons may designate doctors as "guards" who, in addition to the adult protection authority, are authorised to order hospitalisation for a period specified by cantonal law, but not exceeding six weeks. Beyond the specified period, hospitalisation may not continue unless a hospitalisation order from the adult protection authority applies (Art. 430 CC).

The doctor shall examine and interview in person. If possible, he or she shall notify a person closely related to the patient in writing on his or her committal and on the rights of appeal (Art. 431 CC).

C. Restriction of freedom of movement in Residential or Care Institutions

Inspired by German law, special provisions concerning the restriction of freedom of movement in Residential or Care Institutions have existed since 2013:[22]

> **Art. 383 Swiss Civil Code [Restriction of freedom of movement].**
> (1) The residential or nursing institution may restrict the freedom of movement of the person lacking capacity of judgement only if less stringent measures are clearly insufficient or prove to be so and the measure serves to:
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> 1. prevent serious danger to the life or physical integrity of the client or third parties; or

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[20] Full text in English available at <https://www.admin.ch/opc/en/classified-compilation/19070042/index.html> (last visited July 17, 2017).

[21] See in general I. Schwenzer/T. Keller, n. 16 above, pp. 384 et seq.

[22] See in general I. Schwenzer/T. Keller, n. 16 above, p. 381.

> 2. remedy serious disruption to life in and around the institution. …[23]

The competent authority or “guard” in this case is the residential or nursing institution itself.

Conditions for the restriction of the freedom of movement are that the person lacks the capacity of judgement and that the restriction serves the prevention of serious danger to the life or physical integrity of the person or third parties or remedies serious disruption to life in and around the institution. The other condition set out by Art. 383 para. 1 CC, that less stringent measures are clearly insufficient or prove to be so, is a mere declaration of the general principle of proportionality. This declaration was considered important as guidance for those involved in practice.

The safeguarding procedure is generally limited to information and documentation duties. Before the person’s freedom of movement is restricted, it shall be explained to the person concerned what is happening, why the measure has been ordered, how long it is expected to last and who will be responsible for the person concerned during this period (Art. 383 para. 2 CC). Furthermore, a record shall be kept of any measure restricting freedom of movement and the representative in relation to medical procedures shall be notified (Art. 384 para. 1, 2 CC).

The person concerned or a closely related person may submit a written request at any time for the adult protection authority to intervene. In addition, each canton shall make the residential and care institution subject to supervision (Art. 387 CC).

D. Practice

Being driven by the judgments of the European Court of Human Rights, the Swiss legislator always remains one step behind. There are exceptions, especially in the canton of Ticino but, generally, a strong paternalistic tendency is dominant within Switzerland.

Critical points of the new system seem to become the authorisation for “doctors” to order hospitalisation, accompanied by an unsatisfactory safeguarding procedure – and the fact that the appointment of a representative during the person’s stay is only optional.

III. FRANCE

In contrast to Germany and Switzerland and due to a different legislative competence structure, France brought together the traditional strings of provisions concerning deprivation of liberty into one act. These are implemented today in the French Public Health Code (PHC) and were last refined in 2013.[24]

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[23] Full text in English available at <https://www.admin.ch/opc/en/classified-compilation/19070042/index.html> (last visited July 17, 2017).

[24] For (partially outdated) country reports on France in English see for example C. Jonas, A. Machu, V. Kovess, Country report on France, in: Salize, Dreßing, Peitz (eds.), n. 3 above, pp. 75 et seq.; FRA, n. 3 above, Country report on France, full text available at <http://fra.europa.eu/sites/default/files/fra_uploads/2149-mental-health-study-2009-FR.pdf> (last visited July 17, 2017).

A. Hospitalisation

The PHC distinguishes between two types of involuntary hospitalisation: a compulsory hospitalisation at the request of a third party to protect the person's interests (Art. L3212-1 et seq PHC), and a compulsory hospitalisation by official order, to avert danger in the interests of others or the public (Art. L3213-1 et seq PHC). Both methods of hospitalisation are introduced under different conditions.

1. Compulsory hospitalisation at the request of a third party

Compulsory hospitalisation at the request of a third party requires that the person's mental state needs immediate care and constant supervision in a hospital setting (full-hospitalisation) or, introduced by a reform in 2011, "other regular medical supervisions" within the framework of an individual care plan, for example out-patient or part-time care. A mental disorder has to make the person's consent impossible (Art. 3212-1 para. 1 PHC).

The first step in safeguarding these conditions is their further differentiation, on the one hand by emphasising the person's rights, especially his or her right to information and, on the other hand by highlighting the decision guiding principles, in particular the principle of proportionality.

The competent authority or the "guard" who is mandated to decide on the deprivation of liberty is the director of the hospital.

To safeguard the conditions set out by the provisions concerned here, in other words the "interest" of the person, there has to be an application for the deprivation of liberty by a so-called "third party". This could be, for example, due to the important role of the family in French legislation, a family member or another close person who is able to act in his or her interest. The application by a third party can be omitted if imminent danger to the person's health has been established by a doctor. Nevertheless, the director of the hospital has to inform the family or other representatives of the person.

Furthermore, two recent medical certificates verifying the fulfilment of the conditions set out by the legal basis are required. In emergency situations one certificate is sufficient.

Today, the admission is followed by an observation period. In the first twenty-four hours, a psychiatrist must issue a medical certificate, confirming or rejecting the need for hospitalisation. Another examination has to take place within seventy-two hours following admission, concluded by a decision on future hospitalisation or medical surveillance. The director can order continued hospitalisation for up to one month, eventually followed by monthly renewals, always based on a medical certificate. If the duration exceeds one year, each year a committee of three members of the institution has to examine the state of health of the person concerned.

Apart from these administrative safeguards, a decision of the French Constitutional Council in 2010,[25] invoking Art. 66 of the Constitution and its requirement that any

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[25] French Constitutional Council (Conseil constitutionnel), Decision no. 2010-71 QPC, 26.11.2010, full text in French available at <www.conseil-constitutionnel.fr/decision/2010/201071qpc.htm> (last visited July 17, 2017).

deprivation of freedom has to be subject to the control of the judicial authority,[26] forced the French legislator to include a new element in this safeguarding process: full hospitalisation can only be continued if it is permitted by the liberty and custody judge within the first twelve days of hospitalisation. Another decision upon admission has to take place within the next six months.

2. Compulsory hospitalisation by official order

Compulsory hospitalisation by official order requires that a “mental disorder requires treatment” and “jeopardises the safety of others or seriously threatens public order” (Article L3213-1 para. 1 PHC).

The competent authority, or the “guard” in this case, is the local Prefect, in other words the State's representative.

The Prefect’s decision on the admission is based on a medical certificate. In the case of imminent danger, confirmed by a medical certificate, it is the mayor (or in Paris the police commissioner) who can decide on provisional placement measures, but he or she has to inform the Prefect within twenty-four hours.

The observation period after admission is the same as in the case of compulsory hospitalisation at the request of a third party. Based on the final report, the Prefect decides on future care and hospitalisation.

3. Information duties

In addition to this safeguarding process there is another layer of safeguarding. The admission process is accompanied by different information duties, informing different administrative and judicial authorities. One example are the County Commissions for Psychiatric Hospitalisations (Commissions départementales des hospitalisations psychiatriques), which are entitled to supervise and, in special cases, to visit the establishment, to assess the person’s situation and apply to the judge for the termination of the measures taken. Nevertheless, in practice, they are often considered to be too reserved and there are doubts concerning their independence, as it is the Prefect who appoints most of the members of the commission.[27]

B. Other Limitations

Besides these provisions, in France there is no explicit regulation of deprivation or limitation of liberty in a health and social care context. In particular, concerning the limitation of liberty by bedrails or wheelchair straps in nursing homes for example, in France there only exist codes of best practice as “safeguards” – supported by administrative and judicial authorities supervising the establishments.[28] The legal basis for such deprivation of liberty shall determine the establishment’s own regulation

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[26] Full text of the Constitution of October 4, 1958 in English available at <http://www2.assemblee-nationale.fr/langues/welcome-to-the-english-website-of-the-french-national-assembly> (last visited July 17, 2017).

[27] See FRA, n. 24 above, N. 47.

[28] For a critique see Contrôleur general des lieux de privation de liberté, ‘Isolation and restraint in mental health institutions‘, full text in English available at http://www.cglpl.fr/wp-content/uploads/2012/12/CGLPL_Report_Isolation-and-restraint-in-mental-health-institutions.pdf (last visited July 17, 2017).

or the contract with the person concerned, each of which is more clearly specified in the so-called patient's handbook.[29]

C. Practice

In French legislation, the role of the judge becomes more and more important, in the light of constitutional provisions enforced by the French Constitutional Council. Nevertheless, it remains an administration-based system.

After several amendments,[30] especially to close some backdoors provided by fast track procedures, the exception of "imminent danger" to the common procedure of compulsory hospitalisation at the request of a third party seems to become the new Achilles heel of the French system. Significant regional differences in the application of this exception are already ascertainable. However, the French system's main problem today seems to be the emphasis on security aspects, accompanied by the recent expansion of high-security units in French public psychiatric hospitals for patients with dangerous behaviour. This threatens to tip the scales to the disadvantage of the person concerned.[31]

IV. AUSTRIA

In Austria the right to liberty and security is laid down in the Federal Constitutional Law on the Protection of Personal Liberty.[32] In 1990, last amended in 2010, an Act on Compulsory Admission of Mentally Ill Persons (Hospitalization Act, HA) was enacted and, in addition, in 2005, an Act on the Protection of the Personal Freedom of Residents of Homes and other Nursing and Care Facilities was enacted.[33]

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[29] For recommendations and proposals concerning the patient's handbook see in French <http://social-sante.gouv.fr/IMG/pdf/Elaborer_et_diffuser_le_livret_d_accueil_des_personnes_hospitalisees_-_recommendations_et_propositions-2.pdf> (last visited July 17, 2017).

[30] See on their impact for example M. Coldefy, T. Tartour, C. Nestrigue, 'From Compulsory Psychiatric Hospitalisation to Compulsory Treatment: First Results Following the Institution of the Law of July 5th 2011', Questions d'économie de la Santé, no. 205 (2015), full text in English available at <http://www.irdes.fr/english/issues-in-health-economics/205-from-compulsory-psychiatric-hospitalisation-to-compulsory-treatment.pdf> (last visited July 17, 2017).

[31] See for example French Contrôleur general des lieux de privation de liberté, Opinion of 17th January 2013 concerning unjustified stays in Units for Difficult Psychiatric Patients (UMD), full text in English available at <http://www.cglpl.fr/wp-content/uploads/2012/12/AVIS_UMD_20130124_EN.pdf> (last visited July 17, 2017); see also L. Velpry, B. Eyraud, 'Confinement and Psychiatric Care: A Comparison Between High-Security Units for Prisoners and for Difficult Patients in France', Culture, Medicine and Psychiatry (2014) 38, pp. 550 et seq.; A.M. Lovell, L.A. Rhodes, 'Psychiatry with Teeth: Notes on Coercion and Control in France and the United States', Culture, Medicine and Psychiatry (2014) 38, pp. 618 et seq.

[32] Full text available at <https://www.ris.bka.gv.at/Dokumente/Erv/ERV_1988_684/ERV_1988_684.pdf> (last visited July 17, 2017).

[33] For (partially outdated) country reports on Austria in English see for example P. König, Country report on Austria, in: Salize, Dreßing, Peitz (eds.), n. 3 above, pp. 75 et seq; FRA, n. 3 above, Country report on Austria, full text available at <http://fra.europa.eu/sites/default/files/fra_uploads/2137-mental-health-study-2009-AT.pdf> (last visited July 17, 2017).

A. Compulsory Admission Act

The Act on the Hospitalization of Mentally Ill Persons allows for an involuntary placement and deprivation of personal freedom in a psychiatric institution.[34]

The involuntary placement requires that there is reason to assume that due to the person's mental "illness" his or her life or health, or the life or health of others, is seriously and severely at risk and there is no other appropriate possibility of medical treatment or care.

The competent "guard" is the head of the psychiatric institution. In general, only a physician in the public health service or a police physician can decide or order that a person is brought to a psychiatric institution. In hospital, the head of department has to conduct a medical inspection to inform the person concerned and to notify the person's relatives as well as the judge.

The court has to gain a personal impression of the person, inform him or her about the proceedings and hear him or her within four days. If the court deems a placement justified, it must hold oral proceedings within fourteen days.

One of the main Austrian safeguards is the ex lege representation of the person by a so-called Patient Advocate. Patient Advocates represent the person during the whole process and duration of the hospitalisation and are meant to mobilise the person's individual rights.

B. Act on the Protection of Personal Freedom of Home Residents

The Act on the Protection of the Personal Freedom of Residents of Homes and other Nursing and Care was last amended in 2010. It regulates the conditions of restrictions of the resident's freedom by, for example, bed rails, wheelchair straps, trick locks, etc.[35]

Conditions of the restrictions are the mental illness or mental disability of the resident and that, due to this, his or her life or health, or the life or health of others, is seriously and severely at risk. Furthermore, it is a requirement that there is no other appropriate way of avoiding this risk.

The competent "guard" is, in the case of medical restraints, a doctor; in the case of care related restraints, a specially trained person appointed by the establishment; and in institutions caring for mentally handicapped persons, the person in charge of the institution.

In addition to the resident's right to appoint a representative to assert his or her right to personal freedom, he or she is ex lege represented by so-called resident representatives, who are entitled to visit the establishment to get a personal impression of the resident, to inspect relevant documents and to discuss the measures with the competent "guard". Like the resident himself or herself and the head of the

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[34] See also A. Leischner, C. Zeinhofer, C. Lindner, C. Kopetzki, *Medical Law in Austria*, 2nd edition, 2014, N. 293 et seq.

[35] See also A. Leischner, C. Zeinhofer, C. Lindner, C. Kopetzki, n. 34 above, N. 299 et seq.

department, the representative is entitled to request the court to review the restriction of liberty measure.

C. Practice

In practice, there is a broad awareness of the UN Convention on the Rights of Persons with Disabilities. And, different from other countries, the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment is considered even in Austrian case-law.

Nevertheless, there are, other than in Austrian guardianship law, no plans to amend legislation. Efforts are made more towards the optimisation of the existing safeguarding system. Its driving force today are the Patient Advocates. These flood the courts with complaints, particularly following amendments to legislation in 2010. This is a seriously costly "problem" of the Austrian System today but there are not yet any reform plans.

V. SPAIN

In the case of Spain, the most recent reform of deprivation of liberty safeguards happened in July 2015.[36] Differing from France and Austria, the regulation is systematically rooted in private (procedural) law. Special provisions concerning the *restriction* of liberty do not generally exist.

> **Article 763. Non-voluntary hospitalisation due to mental disorders.**
>
> 1. The hospitalisation of a person due to mental disorders who is not in a condition to decide for himself/herself, even should he/she be subject to parental authority or guardianship, shall require court authorisation, which shall be obtained from the court of the place of residence of the person affected by such hospitalisation.
>
> Authorisation shall be obtained prior to hospitalisation, unless reasons of urgency should make it necessary to adopt the measure immediately. In such case, the manager of the centre at which patient was admitted shall give the competent court notice thereof as soon as possible and, in any event, within twenty-four hours, so that the court may proceed to ratify the measure, which must take place within no more than seventy-two hours from the time the court was made aware of the hospitalisation. …
>
> 3. Prior to granting authorisation for or ratifying a hospitalisation that has already taken place, the court shall hear the person affected by such decision, the Public Prosecution Service and any another person whose appearance it may deem appropriate or may be requested by the person affected by the measure. Furthermore, the court shall examine the person hospitalised and hear the opinion of the physician in whose care he/she has been entrusted, notwithstanding taking any other evidence it may deem relevant for the case. In all such procedures, the person affected by the hospitalisation measure shall be entitled to representation and defence … [37]

Spanish law allows for the hospitalisation of a person who has a mental disorder and who is not in a condition to decide for himself or herself. The interests protected are

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[36] For (partially outdated) country reports on Spain in English see for example F. Torres-Gonzalez, Country report on Spain, in: Salize, Dreßing, Peitz (eds.), n. 3 above, pp. 131 ff.; FRA, n. 3 above, Country report on Spain, full text available at <http://fra.europa.eu/sites/default/files/fra_uploads/2146-mental-health-study-2009-ES.pdf> (last visited July 17, 2017).

[37] Full text in English available at <http://www.mjusticia.gob.es/cs/Satellite/Portal/es/servicios-ciudadano/documentacion-publicaciones/publicaciones/traducciones-derecho-espanol> (last visited July 17, 2017).

not closely defined and even Spanish decisions authorising deprivation of liberty show a mixture of different arguments relating to private and public interests.

In general, the competent “guard" is the judge. Authorisation shall be obtained prior to hospitalisation, unless reasons of urgency make it necessary to adopt the measure immediately. In such cases, the manager of the centre at which the patient was admitted shall give the competent court notice thereof as soon as possible and, in any event, within twenty-four hours. This fast-track procedure is used, for example, in the province of Madrid in about 99% of the cases.

In addition, there are the commonly known safeguards, including a hearing of the person affected, their examination and the appointment of a representative. However, this is only the starting point. Recently the constitutional court took a closer look at these provisions. It strengthened the legal provisions with additional court-directed safeguarding processes, including, for example, the requirement for a certain number of medical certificates.[38]

In addition, the Spanish constitutional court judged the provisions concerning deprivation of liberty unconstitutional because of mistakes in the legislation process. As a consequence, the way was cleared for a fundamental revision. There was no shortage of reform proposals as the UN Convention on the Rights of Persons with Disabilities is foremost in today’s discussions.[39]

The Spanish parliament adopted new provisions in July 2015.[40] The formal legislation process doesn’t seem to pose an obstacle this time. The only drawback is that the new provisions are identical to the old ones.[41]

VI. SUMMARY

Taking an overview of the legislation in this sample of countries regarding the deprivation of liberty in mental and social care settings, there is a trend to distinguish between provisions concerning deprivation of liberty by “hospitalisation” and other deprivations or restrictions of liberty. Although jurisprudence and legal literature struggle to delineate deprivation of liberty by hospitalisation from other deprivations or restrictions of liberty, both seem to represent fundamentally different categories. While the starting point, deprivation of liberty, is the same – and conditions therefore are at least similar – it is the safeguarding process that marks their differences.

In particular, there is a trend to emphasise the role of the judge, or at least an independent person, but there is no consensus as to whether the judge should play a role in the admission or control process. Each national legislation tries to reconcile its problems with special fast track procedures or explicit deadlines for the decision of the court. The judge does not replace the *medical* experts, but is considered a neutral,

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[38] Spanish Constitutional Court, Sentencia 141/2012, full text available in Spanish at < http://hj.tribunalconstitucional.es/en/Resolucion/Show/22988> (last visited July 17, 2017).

[39] For example, in Spanish, J. Pallarés Neila, ‘Podrias decirme, por favour, qué camino he de tomar para salir de aquí’, Rev. Asoc. Esp. Neuropsiq., 2014; 34 (121), pp. 115 et seq; L.F. Barrios Flores, ‘La regulación del internamiento psiquiátrico involuntario en España: carencias jurídicas históricas y actuales‘, Derecho y Salud 22 (2012) I, pp. 31 et seq.

[40] See Organic Law (Ley Orgánica) 8/2015, 22.7.2015.

[41] See n. 40 above.

independent expert in *supervising* the decision making process. Amongst others this supervision leads in practice to a higher quality of medical expert opinion. However, after having safeguarded even the safeguards, the importance of proper, continuous training of each person involved in the process is still frequently pointed out. Nevertheless, the impression remains that this personal aspect and its impact on each individual case hides the fact that the continental European systems themselves are based on a historically founded, objective or sometimes still paternalistic perspective on deprivation of liberty. There might be differences between the national legislations, for example in their use of private or public law mechanisms, regarding the appointment of a representative for the person concerned, or even on the amount of information which the person must receive. But from the today's individual perspective on deprivation of liberty such systems necessarily remain patchwork, taking the wrong starting point.[42]

What does it mean if mental disorder eventually falls away as a condition for deprivation of liberty? The "danger" criteria could take centre-stage – with all its known disadvantages.[43] It might be a step forward to break down the "danger" criterion into its elements: into a situation that will result with sufficient probability in damage to one of the interests protected by law, while the notion of "interest" could serve as a link to future developments in other questions concerning self-determination, as in guardianship or contract law. At the end of the day both concepts might not produce large differences in theory but today's practice shows, that at least the above presented European systems are not able to control the centrifugal forces they have released.

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[42] See Committee on the Rights of Persons with Disabilities, *Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities: The Right to Liberty and Security of Persons with Disabilities*, September 2015, paras. 6 et seq < http://www.ohchr.org/Documents/HRBodies/CRPD/GC/GuidelinesArticle14.doc> (last visited July 17, 2017).

[43] For the notion of "dangerousness" see P. Bartlett and R. Sandland, *Mental Health Law: Policy and Practice*, 4th edition, 2014, pp. 239 seqq.