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International Journal of Mental Health and Capacity Law

Articles and Comment

Decision-Making Capacity and the Victorian Mental Health Tribunal

What Makes a "Good" Conference from a Service User Perspective

Why Futile and Unwanted Life-Prolonging Treatment Continues for Some Patients in Permanent Vegetative States (and What to do About it): Case Study, Context and Policy Recommendations

Reviews

Melbourne Social Equity Institute, Unfitness to Plead and Indefinite Detention of Persons with Cognitive Disabilities; and JUSTICE, Mental Health and Fair Trial

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This issue has been edited by:
Professor Jill Stavert (Lead Editor), Simon Burrows, Dr Piers Gooding and Dr Giles Newton-Howes.

Editorial assistance has been provided by:
Hal (Zhan) Brinton

EDITORIAL

We are delighted to present the fourth issue of the International Journal of Mental Health and Capacity Law. The journal is now regularly receiving excellent submissions on mental health and capacity law and practice from across the globe, several of which are published in this issue, and clearly demonstrates the cross-sectorial demand for such a periodical.

Largely driven by the UN Convention on the Rights of Persons with Disabilities (CRPD)[1] and Committee on the Rights of Persons with Disabilities, but also increasingly by other international human rights commentators such as the current Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of health[2], all jurisdictions are being challenged to consider what equality and non-discrimination in the enjoyment of human rights actually means for persons with lived experience of cognitive, intellectual and psychosocial disabilities. What this should, and must, look like in terms of assessments of mental capacity, respecting and supporting individual autonomy and inclusion continues to be an important source of discussion amongst and between academics, practitioners, policy-makers, legislators and persons with lived experience of cognitive, intellectual and psychosocial disabilities. In Scotland, my own jurisdiction, important questions have been asked in recent years about whether, and how, our capacity and mental health legislation does or can be made to respect CRPD standards[3]. This is also currently being considered by the Scottish Government in its plans to reform the Adults with Incapacity (Scotland) Act 2000[4]. The articles and review in this issue cover important aspects of the ongoing CRPD discussion.

With Article 12 CRPD in mind, Chris Maylea and Chris Ryan discuss in ‘Decision-Making Capacity and the Victorian Mental Health Tribunal’ their research into the extent to which the Victorian Mental Health Tribunal in Australia actually gives effect to Victoria’s Mental Health Act 2014 requirement that it must consider a person’s decision-making capacity when determining least restrictive treatment options and to respect a person’s competent refusal of treatment in all but very limited circumstances.

Inclusivity, equality, non-discrimination and the removal of obstacles to rights enjoyment in the context of academic conference attendance and organisation are considered by Sarah Gordon and Kris Gledhill in ‘What makes a ‘good’ conference from a service user perspective?’ They examine relevant CRPD standards and identify a rights framework for those who experience psychosocial/mental impairment and who attend

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[1] (United Nations [UN]) 2515 UNTS 3, UN Doc A/RES/61/106, Annex, GAOR 61st Session Supp 49, 65. (Adopted) 13th Dec 2006, (Opened For Signature) 30th Mar 2007, [Entered into Force] 3rd May 2008.

[2] United Nations Human Rights Council, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of health, 35th Session, 6-23 June 2017, UN Doc A/HRC/35/21.

[3] Martin W, Michalowski S, Stavert J, Ward A, Ruck Keene A, Caughey C, Hempsey A and McGregor R, *The Essex Autonomy Project Three Jurisdictions Report: towards compliance with CRPD Art. 12 in capacity/incapacity legislation across the UK,* (June 2016); McKay C (Mental Welfare Commission for Scotland) and Stavert J (Centre for Mental Health and Capacity Law, Edinburgh Napier University), *Scotland’s Mental Health and Capacity Law: the Case for Reform*, (May 2017).

[4] Scottish Government, *Adults with Incapacity (Scotland) Act 2000: Proposals for Reform*, Consultation Paper, (January 2018).

academic conferences with corresponding obligations on those who organise conferences and/or those with responsibility for regulating conference attendance environments.

Difficult ethical, policy and practice issues that arise in relation to continuing treatment for patients with disorders of consciousness over an extended period of time are considered by Jenny Kitzinger and Celia Kitzinger in 'Why Futile and Unwanted Life-Prolonging Treatment Continues for Some Patients in Permanent Vegetative States (and What to do About it): Case Study, Context and Policy Recommendations. This discussion is contextualised by referring to the case of a patient named 'G' for the purpose of the article and their wider research concerning the treatment of severely brain injured patients. They ask whether such prolonged treatment actually reflects the patient's wishes and best interests and make recommendations as to how such situations may be addressed.

Finally, discussion of CRPD requirements in the context of criminal justice and criminal responsibility has tended to lag slightly behind CRPD discussion in relation to civil matters. However, this is starting to change and is reflected in Kris Gledhill's review of the Melbourne Social Equity Institute report, 'Unfitness to Plead and Indefinite Detention of Persons with Cognitive Disabilities' (published Melbourne, 2017) and the Justice Report 'Mental Health and Fair Trial' (published London, 2017). In this context, he notes and discusses the relevance of the right to equal access to justice in Article 13 CRPD, which requires procedural and age-appropriate accommodations, and the right to liberty in Article 14 CRPD, which requires equal protection against arbitrary detention and that a deprivation of liberty should not be justified on the basis of the existence of a disability.

In closing I would like to thank and acknowledge the support and input provided by the rest of our international and multi-disciplinary editorial team for this final issue of 2017 - Simon Burrows, Dr Piers Gooding and Dr Giles Newton Howes - as well as the overall guidance provided by Kris Gledhill as Editor-in-Chief. Our considerable thanks and appreciation must also go to our reviewers and to Hal (Zhan) Brinton (University of Leeds) for providing the proof-reading and formatting of this issue.

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DECISION-MAKING CAPACITY AND THE VICTORIAN MENTAL HEALTH TRIBUNAL

CHRISTOPHER MAYLEA AND CHRISTOPHER JAMES RYAN*

ABSTRACT

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) has led to a re-thinking of traditional mental health law around the world. Since Australia's ratification of the CRPD, all but one of its eight jurisdictions have introduced reforms to mental health legislation. These are aimed, in part, towards compliance with the Conventions articles. This paper examines the meaning and operation of the reforms introduced in Australia's second most populous state – Victoria.

We first describe the criteria for involuntary treatment set out in the new *Mental Health Act 2014* (Vic) (Austl.) (the Act). We then argue that when making an order for Involuntary Treatment, the Victorian Mental Health Tribunal (the Tribunal) is obliged to carefully consider a person's decision-making capacity as part of ensuring that treatment is provided in the least restrictive way, and to only authorise the involuntary treatment over a person's competent objection in very limited circumstances.

Having established the way in which the Act *should* operate, we then present two empirical studies which analyse the decisions of the Statements of Reasons of the Tribunal to gain some appreciation of how the Act is working. These indicate that seldom does the Tribunal consider the decision-making capacity of people brought before it, and that, even when this is considered, the relevant information is not being used protectively so as to uphold a right to competently refuse treatment. Instead, the Tribunal uses the presence or absence of decision-making capacity, insight or poor judgement, to determine if a person is mentally ill or if treatment is required to prevent serious harm. We conclude that the Tribunal's practice is inconsistent with the principles of the Act and consequently the intention of Parliament.

I. INTRODUCTION

It is well established that an adult's competent refusal of general medical treatment must be respected. This is the case, even if that refusal might be regarded as foolish or irrational and even if it will result in the person suffering serious harm, or even death.[1] Generally, an adult may only be given medical treatment contrary to her/his stated objection, if it can be shown that the person lacks decision-making capacity around that decision. That is to say, it must be shown that the person either cannot comprehend and retain the information relevant to the decision or cannot use and

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[1] *Re T (Adult: Refusal of Treatment)* [1992] EWCA Civ 18; [1993] Fam 95 ('*Re T*'); *Re MB (Medical Treatment)* [1997] EWCA 3093; [1997] 2 F.L.R. 426.

weigh that information.[2] Until very recently this strong legal principle did not apply to psychiatric treatment in Australia. Prior to 2013 no Australian jurisdiction used the presence, or absence, of decision-making capacity as a deciding factor for the imposition of treatment without consent.[3]

In July 2008, Australia ratified the UN Convention on the Rights of Persons Disabilities (CRPD)[4] and since that time, as each Australian jurisdiction has reformed its mental health legislation, those reforms have been motivated, in part, by the articles of the Convention and a desire to address the disparities regarding the role of decision-making capacity.[5] The meaning of the CRPD with respect to involuntary psychiatric treatment is not straightforward and has led to considerable debate.[6] However, almost everyone has concluded that art 12(2) of the instrument ("States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life"), requires that recognition of the right of competent adults to refuse psychiatric treatment.

Four jurisdictions – Queensland, South Australia, Tasmania and Western Australia – have attended to the matter by reforming their mental health legislation so that a competent mentally ill person can refuse psychiatric treatment.[7] The Australian Capital Territory, New South Wales and Victoria have approached this disparity by a series of different, less straightforward, reforms.[8]

In this paper, we consider the Victorian *Mental Health Act 2014* as a case study illustrative of the current tensions in considering decision-making capacity and mental health legislation. This Victorian case study has implications for other jurisdictions, as studies have shown that many people, both in inpatient units and on community

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[2] *Hunter and New England Area Health Service v A* [2009] NSWSC 761.

[3] Christopher James Ryan, 'Capacity as a Determinant of Non-Consensual Treatment of the Mentally Ill in Australia' (2011) 18(2) *Psychiatry, Psychology and Law* 248.

[4] (United Nations [UN]) 2515 UNTS 3, UN Doc A/RES/61/106, Annex, GAOR 61st Session Supp 49, 65. (Adopted) 13th Dec 2006, (Opened For Signature) 30th Mar 2007, [Entered into Force] 3rd May 2008.

[5] See for example: Australian Capital Territory Parliamentary Counsel, *Revised Explanatory Statement, Mental Health (Treatment and Care) Amendment Bill 2014* (2014); NSW Ministry of Health, Review of the NSW Mental Health Act 2007. Report for NSW Parliament: May 2013. Summary of Consultation Feedback and Advice (2013); Panayiotis Tylllis, The Review of the Mental Health Act 2009. A Report by the Chief Psychiatrist of South Australia (2014); *Explanatory Guide, Mental Health Bill* (Tas) *2011 (Exposure Draft)* (2011); State Government of Victoria, *Exposure Draft Mental Health Bill 2010. Explanatory Guide* (2010); *Explanatory Memorandum, Mental Health Bill 2013* (WA) (2013).

[6] Sascha M Callaghan and Christopher Ryan, 'An Evolving Revolution: Evaluating Australia's Compliance with the Convention on the Rights of Persons with Disabilities in Mental Health Law' (2016) 39 *University of New South Wales Law Journal* 596.

[7] These jurisdictions have incorporated a new criterion into the criteria that must be met to provide involuntary treatment that requires that the person lack decision-making capacity. See for example: *Mental Health Act 2016* (Qld) s 12(1)(b); *Mental Health Act 2009* (SA) s 21(1)(ba), as inserted by, *Mental Health (Review) Amendment Act 2016* (SA) s 17(3); *Mental Health Act 2013* (Tas) s 40(e); *Mental Health Act 2014* (WA) s 25(1)(c).

[8] New South Wales, for example, inserted a new mental health principle into its Act requiring clinicians to make "every effort that is reasonably practicable" to monitor patients' capacity to consent and to obtain consent when developing treatment plans: *Mental Health Act 2007* (NSW) s 68(h1); Christopher James Ryan and Sascha Callaghan, 'The Impact on Clinical Practice of the 2015 Reforms to the NSW Mental Health Act' (2017) 25 *Australasian Psychiatry* 43.

treatment orders, retain decision-making capacity relevant to some decisions about their treatment.[9] This is a question of concern for both those who have capacity and who express a desire to refuse treatment, and those who do not have capacity and are 'voluntarily' receiving it without formal legal authority.[10]

Under the Act, Treatment Orders, facilitating psychiatric treatment without consent, are made by the Victorian Mental Health Tribunal (the Tribunal). The Act has specific mechanisms, which require the Tribunal to make a determination about a person's capacity at hearings authorising electroconvulsive treatment (ECT) and neurosurgery aimed at treating mental illness.[11] ECT and neurosurgery are not considered in this paper, which focuses instead on treatment orders which authorise other involuntary psychiatric treatment and detention for the purpose of providing that treatment. The Act does not specifically require the Tribunal to consider a person's decision-making capacity when deciding whether or not to make an order, but it does require treatment to be provided in the 'least restrictive way possible', with a preference for voluntary treatment.[12]

The first section of this paper will argue that in order to ensure treatment is provided in this least restrictive way, the Tribunal *must* have careful regard to the decision-making capacity of people brought before it and only authorise the involuntary treatment of a person over their competent objection in very limited circumstances.

In the second section, we present findings from two parallel studies that illustrate the way the Tribunal has responded to the issue of capacity when making decisions about involuntary treatment. These studies demonstrate that while the Tribunal rarely considers a person's decision-making capacity in a protective sense, so as to uphold their competent refusal of treatment, it regularly takes into account a person's ability to make decisions when determining if they have a mental illness, or if they require treatment for their mental illness.

II. CAPACITY AND THE ACT

While the Mental Health Act 2014 (Vic) (Austl.) does not provide an absolute right to competently refuse psychiatric treatment, there are a number of factors which suggest that a consideration of the treatment criteria requires, in turn, a consideration of a person's decision-making capacity. Capacity is defined in s 68 of the Act:

> *A person has the* ***capacity to give informed consent*** *under this Act if the person—*
>
> *(a) understands the information he or she is given that is relevant to the decision; and*
> *(b) is able to remember the information that is relevant to the decision; and*

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[9] David Okai et al, 'Mental Capacity in Psychiatric Patients' (2007) 191(4) *The British Journal of Psychiatry* 291; Duncan Milne, Anthony O'Brien and Brian McKenna, 'Community Treatment Orders and Competence to Consent' (2009) 17(4) *Australasian Psychiatry: Bulletin of Royal Australian and New Zealand College of Psychiatrists* 273.

[10] Beth Ranjit, 'Can the Use of the Mental Health Act Be the "Least Restrictive" Approach for Psychiatric in-Patients?' (2016) 2016 (22) *International Journal of Mental Health and Capacity Law* 51.

[11] *Mental Health Act 2014* (Vic) ss 96, 102.

[12] *Mental Health Act 2014* (Vic) s 11(1)(a).

> *(c) is able to use or weigh information that is relevant to the decision; and*
> *(d) is able to communicate the decision he or she makes by speech, gestures or any other means.*

As with other Australian mental health Acts, the Victorian legislation provides that a person may only be subject to involuntary treatment if certain criteria are met. These qualifications are set out in s 5:

> *The **treatment criteria** for a person to be made subject to a Temporary Treatment Order or Treatment Order are—*
>
> *(a) the person has mental illness; and*
> *(b) because the person has mental illness, the person needs immediate treatment to prevent—*
> *(i) serious deterioration in the person's mental or physical health; or*
> *(ii) serious harm to the person or to another person; and*
> *(c) the immediate treatment will be provided to the person if the person is subject to a Temporary Treatment Order or Treatment Order; and*
> *(d) there is no less restrictive means reasonably available to enable the person to receive the immediate treatment.*

We argue that the final criterion, the least restrictive criterion, requires a consideration of a person's decision-making capacity. A competent person is already 'enabled' to receive the immediate treatment, as they are 'able' to make the decision themselves, and receive the treatment voluntarily.[13] As voluntary treatment must be preferred, forcing a competent person to receive treatment will almost never be the less restrictive means available to enable a person to receive medical care.

This reasoning means that the Act requires the Tribunal to consider any assessment of the patient's capacity, and requires that such an assessment has taken place. To understand the role that the presence or absence of decision making capacity plays in whether or not a person with a mental illness can be treated involuntarily under the Act, it is necessary to examine the treatment criteria, especially the least restrictive criterion, in the context of the rest of the Act.

While the process of statutory interpretation is fluid and contested, the Tribunal must adopt a construction of the Act which would 'promote the purpose or object underlying the Act'.[14] This requires an analysis of the relevant provisions of the Act, and other indicators of its purpose.[15] These include other relevant provisions of the Act, the intention of Parliament, other laws and international treaties, and relevant case law.

III. THE PROVISIONS OF THE ACT

Perhaps the most relevant provision of the Act in considering capacity is s 70(1), which requires that '[b]efore treatment or medical treatment is administered to a person in accordance with this Act, the informed consent of the person must be sought' and '[t]he person seeking the informed consent of another person to a treatment or medical

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[13] The definition of the word, 'enable', is 'to make able; give power, means, or ability to; make competent; authorise' Macquarie Dictionary, *Enable* (Macquarie Dictionary Publishers, 2017).

[14] *Interpretation of Legislation Act 1984* (Vic) s 35(a).

[15] Michelle Sanson, *Statutory Interpretation* (OUP Australia & New Zealand, 2012).

treatment must presume that the other person has the capacity to give informed consent'. This presumption of capacity clearly applies to psychiatrists and other treating clinicians empowered by the Act, but can also be read to bind the Tribunal, as the making of a treatment order is a necessary precursor to administering compulsory treatment. If s 70(1) is held to bind the Tribunal, the Tribunal must seek the informed consent of people who it considers making orders about, and presume that the person has capacity.

Supporting this interpretation, s 55 requires the Tribunal to have regard to 'the person's views and preferences about treatment of her/his mental illness and the reasons for those views and preferences...'. In the context in which the Tribunal operates, it seems impossible to have regard to a person's views about treatment and the reasons for those views, without considering their capacity to consent to that treatment.

In addition to ss 55 and 70, the Act sets out clear objectives in s 10, including "to enable and support persons who have mental illness or appear to have mental illness ... to make, or participate in, decisions about their assessment, treatment and recovery" and "to protect the rights of persons receiving assessment and treatment". Similarly, the mental health principles, in s 11, require that people "be involved in all decisions about their assessment, treatment and recovery and be supported to make, or participate in, those decisions, and their views and preferences should be respected". They must also "be allowed to make decisions about their assessment, treatment and recovery that involve a degree of risk" while they "have their rights, dignity and autonomy respected and promoted".

The objectives and principles of the Act strongly reinforce the presumption that a patient's competent refusal should carry considerable weight when the Tribunal decides whether there is no less restrictive way for the patient to be treated, even in the face of an envisaged harm that might result from that refusal. One purpose of the Act is to protect human rights, including the right to make decisions about treatment – a right generally enjoyed by all competent Victorians with respect to medical treatment, and a right which the Tribunal has a responsibility to safeguard.

IV. THE INTENTION OF PARLIAMENT

Introducing the *Mental Health Bill 2014* (Vic) ("the Bill") into Victorian Parliament, the Health Minister proclaimed that it was "about maximising individual choice, autonomy, opportunity and wellbeing during a person's life" and that at "the very heart of the bill" was a supported decision making model that would "enable patients to make or participate in decisions about their assessment, treatment and recovery and to be provided with the support to do so".[16] In doing so the Minister highlighted the fact that under the Act, patients would "be presumed to have capacity to make their own treatment decisions" though that presumption could be displaced. She also noted that a person may only be made subject to an involuntary order "if there is no less restrictive means reasonably available to enable the person to be assessed or treated" and that this includes "whether the person can receive mental health treatment voluntarily".

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[16] Victoria, *Parliamentary Debates,* Legislative Assembly, 20 February 2014, 470 (Mary Wooldridge).

Despite this, the Minister endorses the fact that the Act would also facilitate the treatment of some people despite a competent objection, stating that this was “necessary to ensure that patients receive treatment at times when … the person needs treatment to prevent serious harm to the person or another person or to prevent serious deterioration in the person's mental or physical health”.[17] The use of the word ‘ensure’ here is inconsistent with the wording of the Act, which does not ‘ensure’ that people receive treatment, but ‘enables’ it.

Reading these somewhat contradictory aims together, it appears that the intention of Parliament was to only allow the override of competent refusal in a very limited set of circumstances when treatment was necessary to ensure the prevention of serious harm.

V. OTHER LAW

In the second reading speech, the Government also claimed that the Bill was compatible with the *Charter of Human Rights and Responsibilities Act 2006* (Vic) (Austl.).[18] Section 32 of the Charter stipulates that “[s]o far as it is possible to do so consistently with their purpose, all statutory provisions must be interpreted in a way that is compatible with human rights” and that “International law … relevant to a human right may be considered in interpreting a statutory provision”.

This allows the consideration of art 12 of the CRPD, which requires that states ensure that ‘persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life’ and to 'take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’. An analysis of the compliance of the Act with the CRPD has been undertaken elsewhere,[19] but any analysis would indicate that it requires States Parties to ensure that a person is as able as possible to participate in their own decision making. This must include some consideration of a person’s decision-making capacity.

The Act, read as a whole, restricts the cases where a competent decision can be overridden to options of last resort – quite literally the least restrictive option. Even if a person is assessed as requiring support to exercise their decision-making capacity, or is assessed as needing to have a substituted decision-maker, an assessment of capacity must take place at some point.

What little case law exists supports this analysis.[20] To date no court of record has ruled

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[17] Victoria, *Parliamentary Debates,* Legislative Assembly, 20 February 2014, 475 (Mary Wooldridge).

[18] Ibid.

[19] Chris Maylea and Asher Hirsch, 'The right to refuse: The Victorian Mental Health Act 2014 and the Convention on the Rights of Persons with Disabilities' (2017) 42(2) *Alternative Law Journal*.

[20] There is an automatic right to have decisions of the Tribunal reviewed by the Victorian Civil and Administrative Tribunal (VCAT) under s 201 of the Act. This review is not an appeal, but a *de novo* hearing, which is in turn appealable, by leave, to the Victorian Supreme Court or Court of Appeal. While a theoretical avenue for review of a Tribunal decision may rest in the inherent jurisdiction of the Supreme Court, under order 56 of the *Supreme Court (General Civil Procedure) Rules 2005* (Vic), in

on the way the treatment criteria are applied, and only one has been decided by the Victorian Civil and Administrative Tribunal (VCAT). This case, *WCH v Mental Health Tribunal (Human Rights)*,[21] is entirely consistent with the reading of the Act proposed here.

WCH was a gentleman diagnosed with schizophrenia who had been subject to Community Treatment Orders (CTOs) made by the Tribunal and its predecessor (the Mental Health Review Board), for 16 years. WCH did not believe himself to have schizophrenia but agreed he had been depressed from time to time and was willing to take treatment for this. WCH felt the CTO infringed "his freedom of thought and rights"[22] pursuant to the 2006 Charter and wanted it set aside. He proposed that he would slowly decrease his current antipsychotic medication and voluntarily undergo supervision by his current treating team for a year to allow monitoring for relapse. In revoking the order, the presiding Member emphasised being "satisfied that, having regard to WCH's intention to undertake a managed and supervised medication reduction under the care of the service – a course of action which has been described as *'a reasonable therapeutic strategy'* – there is a less restrictive means of treatment available to WCH and so that criterion is not met".[23]

In addressing the least restrictive criterion specifically, and having noted that the independent expert psychiatrist had consider WCH's plan "a reasonable option", the Member opined:

> Allowing WCH to become a voluntary patient engaging in treatment in order to reduce and potentially eliminate the medication he has been receiving for 16 years is consistent with his dignity as a person and principle 1(d). That is because it would allow him to make decisions about his own treatment and recovery having assessed the risk associated with that treatment. It would also be consistent with VCAT's section 55(2) obligation to take into account WCH's views and preferences and WCH's Charter rights[24]

The Member also declared herself satisfied that WCH had "the capacity to give informed consent to this course of action in the way discussed in sections 68 and 69" [25] of the Act [107], and noted that "[i]n that light, WHC falls squarely within the MH Act's objective of being treated in the least restrictive way possible with the least possible restrictions on his Charter rights and human dignity".[26] She continued, "It is also consistent with the MH Act's objectives to enable people to make and participate in decisions about treatment and recovery and to promote recovery".

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practice it is extremely difficult to have a decision of the Tribunal subject to judicial review – only decisions of VCAT. For an example of this occurring in practice in Western Australia, see: *LS-v-Mental Health Review Board* [2013] WASCA 128. Decisions made by VCAT may be persuasive, and strongly influence decisions of the Tribunal, but the Tribunal is not bound by these decisions. Questions of law may be referred by the Tribunal itself to the Supreme Court under s 197 of the Act, however this has not yet occurred. This means that unlike, for example, the English and Welsh Mental Capacity Act 2005, a body of case law for interpreting the Act has not been generated.

[21] *WCH v Mental Health Tribunal (Human Rights)* [2016] VCAT 199.

[22] *WCH v Mental Health Tribunal (Human Rights)* [2016] VCAT 199, para 2.

[23] *WCH v Mental Health Tribunal (Human Rights)* [2016] VCAT 199, para 6.

[24] *WCH v Mental Health Tribunal (Human Rights)* [2016] VCAT 199, para 106.

[25] *WCH v Mental Health Tribunal (Human Rights)* [2016] VCAT 199, para 107.

[26] *WCH v Mental Health Tribunal (Human Rights)* [2016] VCAT 199, para 108.

This clearly supports the argument that an assessment of a person's decision-making capacity should be undertaken when considering which option is the least restrictive. There is nothing in the Act that would prevent the Tribunal from legitimately coming to the view that treatment should be given and override the patient's competent refusal, but the construction of the Act places very significant constraints on the circumstances where this would be a reasonable conclusion to draw.

VI. ARGUMENTS AGAINST

This analysis of the Act which has been put forward is not universally accepted. The main argument against reading a requirement to consider a person's capacity into the least restrictive criterion is that the previous Act, the now repealed *Mental Health Act 1986* (Vic) (Austl.), included a distinct capacity criterion, which is no longer present.[27] Had Parliament intended to require the Tribunal to consider a person's capacity, it would have explicitly said. This is a generally accepted tenant of statutory interpretation, however the 'strongest statutory presumption is that legislation cannot, in the absence of clear words, abrogate fundamental rights.'[28] As the rights of bodily integrity, freedom of movement and competent refusal of medical treatment are fundamental rights, the legislation should be read so as to be compatible with those rights, so far as is possible.

Additionally, the CRPD arguably requires preservation of the legal right to refuse treatment, even when a person lacks decision-making capacity.[29] Despite this apparent inconsistency, the presumption that legislation should be read so as to conform with international law requires that it should be read to be consistent 'as far as its language admits',[30] and an approach which supports competent refusal protects more rights than an approach which ignores it.[31]

As with any process of statutory interpretation, in the absence of judicial consideration, the lower Tribunal is required to interpret the Act as best it can. The remainder of this paper examines how this has played out in practice.

VII. CAPACITY AND THE TRIBUNAL

The Tribunal publishes many of its statements of reasons concerning its determinations. Statements are usually only generated if a party requests one under s 198 of the Act.

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[27] *Mental Health Act 1986* (Vic) s 8(1)(d). Notably this treatment criterion was not of the sort that excluded people who retained decision-making capacity from being subject to involuntary treatment as the reformed treatment criteria in Queensland, South Australia, Tasmania and Western Australia do. Rather it stipulated that for involuntary treatment to be applied it must be the case that "the *person has refused* or is unable *to consent to the necessary treatment* for the mental illness" [emphasis added]. Therefore, it was not a "capacity criterion" in the more contemporary sense: Christopher James Ryan, 'Capacity as a Determinant of Non-Consensual Treatment of the Mentally Ill in Australia' (2011) 18 *Psychiatry, Psychology and Law* 248.

[28] Sanson, above n 15, 206.

[29] Maylea and Hirsch, above n 19.

[30] *Jumbunna Coal Mine NL v Victorian Col Miners Association* (1908) 6 CLR 309, 363.

[31] Maylea and Hirsch, above n 19.

Up until October 2015, it was the Tribunal's practice to publish all such statements of reasons on the Australian Legal Information Institute's (AustLII) website, unless the case was deemed particularly sensitive or difficult to anonymise. After October 2015, the Tribunal changed this practice so that it only publishes statements which meet certain criteria, such as those which address complex or novel legal questions, are informative examples of decision-making and those which highlight the principles of the Act.[32] This means that while they may not be representative of all Tribunal hearings, the selection bias should tend towards decisions which the Tribunal would like to be seen as representative.

This section will now detail the findings of two studies which examined these statements of reasons to determine the way the Tribunal engages with the issue of decision-making capacity.

VII. 1 First Study

The first study aimed to examine the extent to which the presence or absence of decision-making capacity was relevant to the Tribunal's reasoning in its application of the least restrictive criterion as reflected in its statements of reasons.

Method

Consideration of all 206 statements of reasons available as of the 31 July 2016, covering the period from 1 January 2015 to 30 June 2016 which included a determination as to whether the least restrictive criterion had been met. This excluded statements of reasons for electroconvulsive treatment or where the least restrictive criterion was not considered.

The statements of reasons were characterised into five groups as outlined below.

Group 1 consisted of those statements in which the Tribunal clearly noted that it had considered the presence or absence of a patient's decision-making capacity as a factor in its determination of whether the least restrictive criterion had been met.

Group 2 consisted of those statements in which the Tribunal did not refer directly to the presence or absence of decision-making capacity, but did refer to the patient's ability to understand, use and weigh, or recall, information or the ability to communicate a decision, and this appeared to be a factor in the its determination of whether the least restrictive criterion had been met.

Group 3 statements were those in which the Tribunal referred neither to decision-making capacity nor its elements, but made reference to either the patient's beliefs or insight and this reference appeared to be a factor in its determination of whether the least restrictive criterion had been met.

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[32] Grace Horzitski, 'General Enquiry Statements of Reasons on AustLII (Pers. Comms. Mental Health Tribunal)', 16 June 2016.

Group 4 statements were those in which the Tribunal made no reference to any of the concepts mentioned above, but made note of the importance of autonomy, or of the right to take risks, or of the mental health principles in subsections 11(1)(e) or 11(1)(d) that respectively refer to these rights, and this consideration appeared to be a factor in its determination of whether the least restrictive criterion had been met.

Finally, a statement was assigned to Group 5 if none of the above applied. That is, decisions where, with respect to its consideration of the least restrictive criterion, nothing in the Tribunal's statement of reasons contained a suggestion that the patient's decision-making capacity had been considered.

A statement of reasons was only allocated to one of the first four groups if it was clear that the concepts relevant to each group formed part of the Tribunal's rationale for finding the least restrictive criterion either was met or not met. If, for example, the Tribunal reported that the patient's legal representative had argued that the patient "understood" h/she was ill or needed treatment, but the Tribunal had not appeared to refer to the patient's understanding as a relevant factor in its determination, then that decision was allocated to Group 5 not Group 2.

If a case had elements that would allow classification into more than one of the groups above, it was allocated to the group of the smallest number. So, for example, if a statement referred to both a patient's "understanding" and the importance of respecting autonomy, it was assigned to Group 2 rather than 4.

When a Tribunal returned a split decision, as it did in eight of the cases,[33] only the reasoning of the majority was taken into account. The percentage of times the Tribunal found that the least restrictive criterion was met and not met was reported for each group.

Results

Cases in Groups 1 and 2 in which it is clear the Tribunal considered decision-making capacity

The presence or absence of the patient's decision-making capacity was explicitly documented as a factor in the Tribunal's determination of whether the least restrictive criterion had been met in only 3 of the 206 cases. In the first of these Group 1 cases,[34] the Tribunal found the patient's "ability to make treatment decisions was impaired due the severity of her mental illness" and related to this, reasoned she "would not be able to receive immediate treatment in a less restrictive manner and that compulsory treatment was required".

In the second, the patient's legal representative submitted that the patient could be

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[33] *WMJ* [2015] VMHT 17; *TMR* [2015] VMHT 22; *WRH* [2015] VMHT 27; *YPQ* [2015] VMHT 105; *VTK* [2015] VMHT 111; *OED* [2015] VMHT 121; *STU* [2015] VMHT 197; *NYN* [2016] VMHT 45.

[34] *WRH* [2015] VMHT 27.

treated voluntarily because she was consenting to treatment.[35] However, the "Tribunal was not satisfied that the patient was able to sustain consent" and in its view the patient's "understanding of her illness and her acceptance of treatment were not sufficiently consistent for her to agree to treatment."

In the third case,[36] the Tribunal focused particularly on the competence of the patient's desire to go overseas for treatment and listed a number of factors relevant to its least restrictive criterion determination that included: his being still unwell and "not in a fit condition to make his own considered decision" on the matter and; his delusions having an "impact on his decision making".

In all three of the cases, the Tribunal found that the patient lacked decision-making capacity (though in none did it use exactly that phrasing) and in all three it found that the least restrictive criterion was met.

In a further 17% of cases (n=36) (Group 2 cases) the Tribunal made reference to one or more of the statutory requirements for "capacity to give informed consent" and it was clear that this had formed a part of its reasoning in relation to whether or not the least restrictive criterion was met. The majority of these Group 2 cases referred to the patient's understanding (or lack of), though a minority referred to the patient's "appreciation" (which by its context appeared to be used in a manner that was similar to "understanding"), or the patient's ability to weigh up[37] information or the patient's "judgement"[38] (which by its context appeared to be used in a manner that was similar to a determination about the patient's ability to use and weigh the information). No case made reference to the patient's ability to either remember the information or communicate the decision – the other elements referred to as required to give informed consent.[39]

By way of example, in one of these Group 2 cases[40] the Tribunal "accepted that [the patient] was now better informed [than on admission] and had gained knowledge and an *appreciation* of her condition".[41] Related to this, the "Tribunal was not satisfied that there were no less restrictive means reasonably available to enable [her] to receive the immediate treatment that she requires", and noted "[s]pecifically, in view of her statements about continuing with treatment, and her positive attitude to her treating team … that a less restrictive option reasonably available at this time was for [her] to be treated as a voluntary patient". The Tribunal also found that it was relevant that the patient's change in attitude was "considered and informed", and related to this, it "was satisfied that [she] could and would accept necessary treatment for her condition without the need for a Treatment Order" and therefore it "was not satisfied that the requirements of section 5(d) were met".

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[35] *MKP* [2015] VMHT 108.

[36] *TBH* [2015] VMHT 144.

[37] *UFG* [2016] VMHT 7.

[38] *SXY* [2015] VMHT 117; *YJW* [2015] VMHT 216.

[39] *Mental Health Act 2014* (Vic) s 68(1).

[40] *AUJ* [2015] VMHT 43.

[41] *AUJ* [2015] VMHT 43 (emphasis added).

In another of these Group 2 cases[42] the Tribunal stated that there was evidence before it which "indicated that [the patient's] understanding of her mental illness and the immediate need for treatment was lacking" and having regard to this and other evidence it "was of the view that [her] immediate need for treatment to stabilise her mental health, could only be obtained pursuant to a Treatment Order". The Tribunal was satisfied that the least restrictive criterion was met in 21 of these 36 Group 2 cases.

Taken together the Group 1 and 2 cases represent the cases where it was clear that Tribunal had made some consideration of the patient's decision-making capacity and that this was relevant to its least restrictive criterion determination. This means that this mode of reasoning was clearly documented in only 19% of cases.

Cases in Groups 3 and 4 in which the Tribunal may have considered decision-making capacity

While not referring to either decision-making capacity or its required elements, the Tribunal indicated that a patient's beliefs or insight was a factor in its least restrictive criterion determination in a further 17% of cases (n=36). In one example of these Group 3 decisions,[43] the Tribunal found the least restrictive criterion was met and that it was relevant to this finding that the patient did not "believe" he had a mental illness and had "little or no insight into his mental illness".

In 31 of these 36 Group 3 cases the Tribunal found the least restrictive was met and only in five did it find it was not met.

Group 4 cases comprised a further 11% (22) of cases. In these the Tribunal made mention of the importance of autonomy or the associated mental health principle (s. 11(1)(e)), or the importance of being allowed to make decisions that involved a degree of risk (almost always in relation to the associated mental health principle (s.11(1)(d)). The extent to which these mentions might have been signifiers of the Tribunal considering the patient's decision-making capacity varied enormously but cases where these concepts were mentioned were included in group 4 unless it was possible to confidently conclude that these concepts were not related to a consideration of decision-making capacity, or not related to the Tribunal's determination on the least restrictive criterion.

In one example of these group 4 cases[44] the Tribunal stated that "[in] coming to its decision [it] was mindful of the principles under the Act, in particular section 11.(1)(d) and (e)" and, by a majority, it found that "immediate treatment for [the patient's] mental illness could occur voluntarily, which involves a degree of risk, but would be less restrictive of [her] autonomy and dignity".

In many of these statements of reasons the reference to the section 11.(1)(d) preceded a conclusion that the risk involved in the patient being made voluntary was relatively

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[42] *DLG* [2015] VMHT 82.

[43] *ANV* [2015] VMHT 95.

[44] *OED* [2015] VMHT 121.

minor. This common approach to documentation likely accounts for the fact that in only 4 of these 22 Group 4 cases did the Tribunal find that the least restrictive criterion was met.

Cases in Group 5 in which there is no evidence the Tribunal considered decision-making capacity

If one combines the cases categorised to Groups 3 and 4, which represent those cases where the Tribunal might have considered the patient's decisions making capacity, with those cases in Groups 1 and 2, where it is clear that the Tribunal did consider the patient's decision-making capacity, it becomes apparent that even under the most generous interpretation of the data, the Tribunal did not consider whether the patient's refusal of the proposed treatment was competent in 53% of the cases reviewed.

In these 109 Group 5 cases, the Tribunal made a determination on the least restrictive criterion without reference to anything that could have signified that it had given consideration to the patient's decision-making capacity. In these cases, if a patient's understanding or appreciation or beliefs or insight was mentioned in statement of reasons at all, that phenomenology was not linked to the Tribunal's rationale for its decision and there was no mention of autonomy or right to take risks that in any way suggested the patient's decision-making capacity had been considered.

Under the reasoning set out above, the only valid reason that the Tribunal might not make reference to the patient's decision-making capacity about the proposed treatment being refused, was if it were to form the view that in this instance the presumption of capacity could not be displaced. However, if it were the case that the patient was competently refusing the proposed treatment then, again using the reasoning above, the Tribunal should have found that the least restrictive criterion was met in only a minority of cases. In fact, the reverse was true. The Tribunal found the least restrictive criterion was met in 92 of the 109 Group 5 cases (84%).

VII. 2 Second Study

The second study was an exploratory thematic analysis, which sought to identify the way the Tribunal made decisions. One of the early emergent themes was 'capacity', which forms the basis of the second study analysis presented here.

Method

The second study reviewed 339 statements of reasons, those hearings held from 2 July 2014 to 1 May 2016. Of these, 45 were excluded, 1 hearing was adjourned, 34 hearings were for ECT applications only, and 10 where applications were made for both ECT and Treatment Orders.

Of the remaining 294, treatment orders were made in 69% (202) cases. Unlike the first study, cases where the least restrictive criterion was not considered were included, on the basis that a person's decision-making capacity may have been assessed in consideration of another criterion.

The samples of the first and second studies overlapped for the period between 1 January 2015 and 1 May 2016, together covering a continuous period between the commencement of the Act on 1 July 2014 through to 30 June 2016. This study consisted of a complete reading of all statements of reasons, using NVivo qualitative data analysis software. This was supplemented by automatic text coding, in this case for words including, 'capacity', 'judgement', 'insight', 'weigh', 'ability', 'consent' and the phrase 'involve a degree of risk'.

Themes were developed using grounded theory, with this examination of capacity forming part of a much larger analysis. Each statement was classified according to various attributes, such as if the person was legally represented, if the order was made out, and which criterion was not made out if the order was not made out.

Themes were identified as having been considered by the Tribunal, irrespective of which party had raised the issue, on the basis that the statement of reasons represents factors which were taken into account in the decision of the Tribunal.

Results

Several themes were developed under the notion of 'decision making', including 'capacity', 'judgement' and 'insight'. The theme of 'capacity' related to explicit considerations of a person's decision-making capacity, and often overlapped with the theme of 'judgement', which related to a value assessment of the decision. The theme of 'insight' related to the degree to which the person agreed with or understood their diagnosis. These three themes can be easily linked to the definition of capacity to give informed consent in s.68 of the Act, which requires understanding of, and the ability to remember and use, the information relevant to the decision.

Similar to the first study, the second study found that the Tribunal only explicitly considered a person's capacity in a very limited number of cases (n=19) (2%). In 89% (n=17) of these cases, the person had legal representation, compared to 68% (n=201) more generally.

In cases where the Tribunal explicitly considered capacity, they made an order in a lower percentage of cases when capacity was considered (63%, n=12) than when it was not (69%, n=202), though given the small sample size this difference is unlikely to be statistically significant.

In every case where capacity was explicitly considered and an order not made (n=7), the criterion which was not met was the least restrictive criterion, compared with 60% (n=51) of the cases where capacity was not explicitly considered and an order was not made (n=85). This suggests some relationship between the way the Tribunal considers capacity and the least restrictive criterion.

The different approach and parameters used for the second study add support to the results of the first study. For example, the second study identified an explicit rejection of the notion that the Tribunal should consider capacity, in *BFW*[45]; 'the Tribunal does not have to decide whether BFW is refusing treatment or is incapable of giving consent to treatment, as was the case under the previous Act.' This approach was repeated in *LAO*[46] in which it was found that unlike under the 1986 Act, under the 2014 Act 'capacity to give informed consent is no longer a determining factor for the Tribunal.' Despite this, the second study found that the Tribunal did occasionally consider a person's decision-making capacity in its consideration of the least restrictive criterion, such as *EPK*[47], where the patient was found to be 'ready and willing to consent to the required treatment as a voluntary patient and would remain in the ward.'

The second study also examined the notion of capacity irrespective of who it was raised by, rather than just considering the decision-making process of the Tribunal.

For example, in *QDE*[48], where the treating team asked for the order to be made so that, among other things, the patient's capacity to consent to treatment could be assessed. QDE's solicitor countered that QDE 'was capable of making an informed decision as to her future treatment'. Legal representatives often raised the issue, such as *MKP*[49], in which the solicitor '...submitted that MKP could be treated voluntarily because she was consenting to treatment.' In response, the Tribunal considered this submission, but 'was not satisfied that MKP was able to sustain consent'. In the Tribunal's view, MKP's understanding of her illness and her acceptance of treatment were not sufficiently consistent for her to agree to treatment.' This is a clear example of the Tribunal engaging in the reasoning laid out above making an assessment of a person's capacity, and making a decision based, in part, on this assessment.

The second study was also not limited to the Tribunal's considerations of the least restrictive criterion. This meant that while it reinforces the conclusion of the first study, that the Tribunal is only rarely considering capacity in determining if treatment is restrictive, it uncovered a tendency to consider capacity in relation to other criteria. Up until this point, we have focused on a person's decision-making capacity to refuse treatment, however the Tribunal considered a person's decision-making capacity in a number of different ways, not just in relation to their ability to refuse treatment.

Poor or impaired judgement was raised in 12% (n=35) of cases, and insight, lacking or otherwise, was considered in 48% (n=141) of cases.

A notable finding of the second study is that the different themes related to capacity were considered under different criteria. As Figure 1 below illustrates, the theme of capacity was most often considered under the least restrictive criterion, whereas, of these three, insight was the factor most often considered in establishing if a person had a mental illness.

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[45] *BFW* [2014] VMHT 17.
[46] *LAO* [2015] VMHT 116.
[47] *EPK* [2015] VMHT 47.
[48] *QDE* [2015] VMHT 207.
[49] *MKP* [2015] VMHT 108.

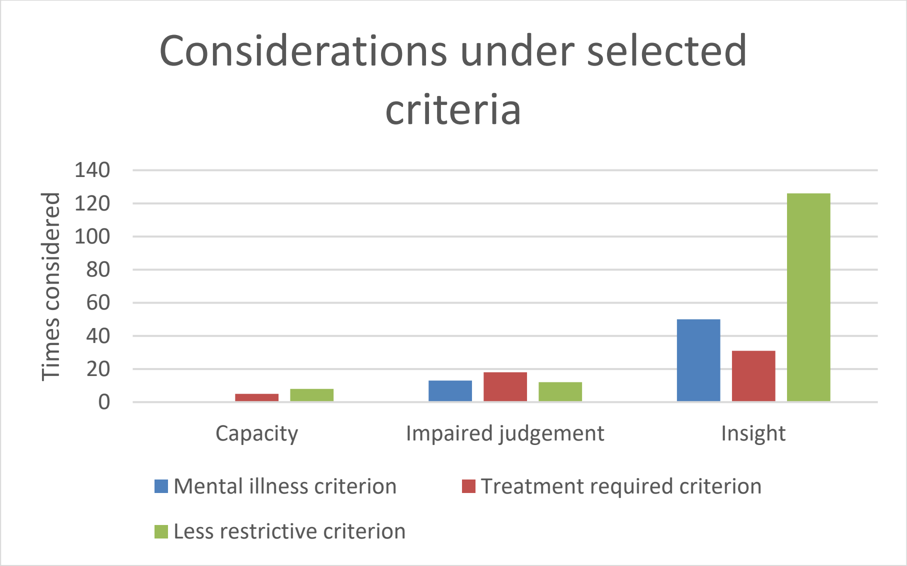

Figure 1 - Considerations under selected criteria[50]

Judgement was considered relatively evenly, but more often in the treatment required criterion. This supports the hypothesis that capacity, or at least a person's judgement or insight, is being considered, but it is being considered when establishing the presence of a mental illness, not as a protective factor in recognising a person's right to competent refusal. It was not possible to clearly determine how the presence of capacity, 'good' judgement or insight was related to the decision, as when these issues were raised, they were usually raised in the context of a disagreement, and the Tribunal only rarely made a specific finding one way or the other. What is clear, is that when these issues were considered, they had some correlation with the outcome of the hearing.

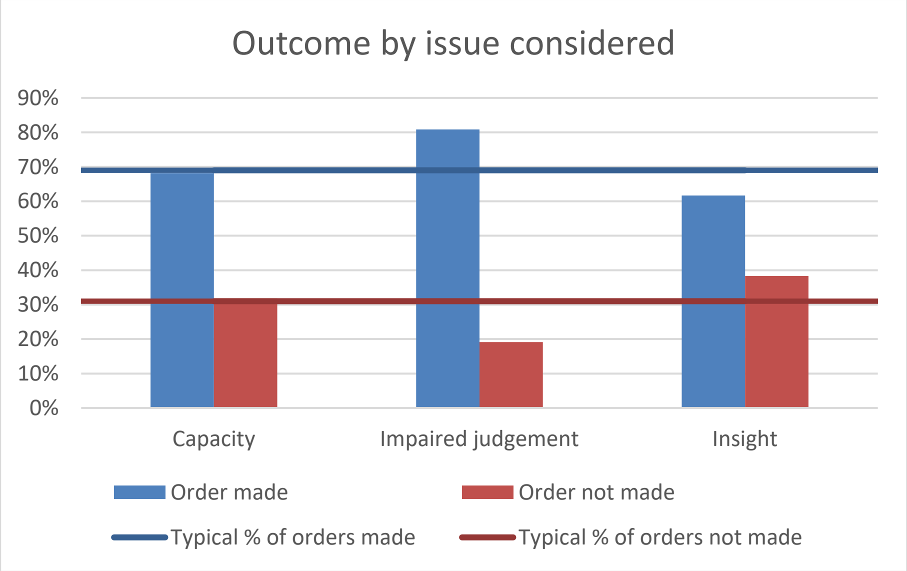

Figure 2 - Outcome by issue considered

As Figure 2 shows, where a person's judgement was considered by the Tribunal, it made 12% more orders than it made on average. In cases where their insight was in

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[50] Note that these considerations may have occurred multiple times in a single statement of reasons.

question, it made 7% fewer orders than it made on average. When the tribunal explicitly considered capacity the outcomes reflected the average frequencies. Again the relatively small numbers mean that these figures did not reach statistical significance.

As Figure 1 illustrates, a person's judgement was regularly (n=43) used to establish the first criterion, that a person had a mental illness. This was evident in *TLX*[51], where both poor decision-making and lack of insight was one of the symptoms identified and relied on as evidence that TLX had a mental illness:

> *He was again admitted to hospital as an involuntary patient. He presented with poor judgement, risky and disinhibited behaviour, and an elevated and expansive mood. He was said to have no insight. After two weeks TLX left hospital against medical advice and declined any ongoing contact with the community mental health service. After one week his wife contacted the mental health service due to TLX engaging in risk taking behaviours, which included driving at high speed with passengers in his car and running red lights. Hs mood was again reported to be elevated, with poor judgement and no insight. He was readmitted to hospital and commenced on a depot anti-psychotic medication.*

At other times, an alleged lack of capacity was used to explain why the Tribunal believed that a person needed treatment to prevent harm to themselves or others, and therefore meet the second treatment criterion. For example, in *UKR*[52], the Tribunal heard that UKR's 'beliefs about how he would be cared for were driven by his persecutory delusions, and he did not have capacity to make decisions of this kind.' Similarly, reduced decision-making capacity was used to explain why less restrictive treatment was not available, in *TBH*[53], where the Tribunal decided TBH could not be treated less restrictively, amongst other considerations, due to:

> *…the fact that TBH is currently still quite mentally unwell and vulnerable, and not in a fit condition to make his own considered decision about whether to travel overseas away from his wife and children; and the fact that TBH is currently suffering from delusional beliefs about his wife which might impact on his decision making.*

As in *TLX,* this was often related to the notion of insight, which was highlighted in the Group 3 cases of the first study. Considering the need for immediate treatment in *OFO*[54], the Tribunal highlighted the connection between insight and consent, viewing insight as a perquisite to consent:

> *OFO, though improved, still needs some assistance with residual symptoms and indicated her intention to co-operate with her general practitioner and the treating team in that regard. Presently, there is a need for immediate treatment to prevent a relapse and continue the improvement made and OFO is receptive to the need for such treatment. She is co-operative to that need for treatment and has sufficient insight to consent and does consent.*
>
> *This criterion is accordingly not met as OFO appreciates the need for immediate treatment and has consented to it and is engaged with the service.*

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[51] *TLX* [2015] VMHT 214.

[52] *UKR* [2016] VMHT 12.

[53] *TBH* [2015] VMHT 144.

[54] *OFO* [2014] VMHT 13.

This indicates a consistent theme in the statements of reasons, which is that a person's capacity to consent to treatment is directly linked with their compliance with the proposed treatment. While compliance and capacity are not treated as synonymous, the Tribunal demonstrates an inclination to accept that people have capacity when they are compliant, and reject that contention when people are not. This can be seen in *MKP*[55], where the Tribunal seems to conflate the two:

> *[MKP's legal representative] submitted that MKP could be treated voluntarily because she was consenting to treatment. The Tribunal was not satisfied that MKP was able to sustain consent. In the Tribunal's view, MKP's understanding of her illness and her acceptance of treatment were not sufficiently consistent for her to agree to treatment. For example, the evidence of all parties showed MKP's ambivalence towards lithium medication, which the treating team considered a cornerstone of her treatment.*

In *MKP*, the Tribunal seems to suggest that insight, characterised as understanding and acceptance, is a precursor to capacity, and relied on this inability 'to sustain consent' as justification for deciding that MKP could not be treated less restrictively.

In other decisions, such as *EPK*[56], the Tribunal separated the 'poor decision making' from the ability to make decisions. The report outlined a series of reasons EPK was at risk:

> *The Report also noted EPK consumed alcohol once whilst out on a group outing against staff advice. EPK struggled to follow given directions. EPK had engaged in inappropriate sexual activities and therefore remained vulnerable due to her poor judgement. EPK had failed to return from unescorted leave at the designated time and had absconded for a few days. EPK had got into cars with strangers. She had befriended strangers, slept in their homes and had a history of vulnerability to males.*

Despite this evidence, the Tribunal declined to make an order based on her willingness and ability to consent to the treatment:

> *The evidence before the Tribunal indicated that EPK's current symptoms were not severe. EPK had a good understanding of the treatment she was receiving and what was proposed by the treating team and she had a clear view in respect to her own recovery objectives. She was ready and willing to consent to the required treatment as a voluntary patient and would remain in the ward.*

What is implied here is not that these people lack decision-making capacity in a strict legal sense, but that the Tribunal does not believe that they will make good decisions, or decisions which the treating team would have preferred they make. This approach was most clear in *WRH* [57]:

> *The majority view was that WRH's ability to make treatment decisions was impaired due the severity of her mental illness. WRH's exclusion of her family, who may have been a protective factor, lead the members to agree that there was no less restrictive option for immediate*

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[55] *MKP* [2015] VMHT 108.

[56] *EPK* [2015] VMHT 47.

[57] *WRH* [2015] VMHT 27.

> *treatment. Accordingly, the majority view was that WRH would not be able to receive immediate treatment in a less restrictive manner and that compulsory treatment was required.*

While the Tribunal states that WRH's ability to make treatment decisions is impaired by her mental illness, what it appears to mean is that WRH's ability to make 'good', or compliant, treatment decisions is impaired. WRH expressed a preference for natural therapies, and stated that her opposition to the proposed treatment was based on long held spiritual beliefs. As outlined above, if WRH did not have a mental illness, and was assessed as having capacity, she would be entitled to refuse the proposed treatment. As the Tribunal has not assessed her capacity, this decision seems to rest only on the subjective assessment of the quality of those decisions. EPK had documented symptomology, but as she was assessed as being likely to comply with treatment, she was viewed as having capacity to make decisions. WRH, with her own symptomology, was viewed as unlikely to comply, and viewed as not having that capacity.

There is a similar conflation of capacity with medication compliance, a topic which dominated many of the statements of reasons, and was considered in 63% (n=186) of all reviewed cases. In *YOB*[58], the Tribunal explicitly linked diminished capacity and the role on the Act in enforcing medication compliance:

> *The Tribunal did not accept the submission that intervention to ensure adherence did not amount to treatment for the purposes of the Act. Indeed, such involvement is often central to the provision of treatment for a person believed to be mentally ill and who may not have their usual capacity to understand and appropriately respond to the need to receive necessary treatment.*

The Tribunal clearly sees a key part of its role as making sure people get the medication they need when they are not able to make 'good' decisions about taking that medication. Sometimes, however, an alternative view was raised, such as by the dissenting member in *WYV*[59], who, in finding the least restrictive criterion was not met, found:

> *…the Tribunal is required to consider the principles of recovery and autonomy within a background of presumed capacity. The relevant principles also include that a person should be allowed to make decisions about their assessment, treatment and recovery that involve a degree of risk. Another way this may be expressed is as a dignity of risk whereby a person may exercise their autonomy and independence by making choices that, in a similar situation, someone else might not make.*

This view, largely consistent with the position put forward in the first section of this paper, is not widely evident in the data. The overall trend illustrated in the second study is that the Tribunal does regularly consider a person's decision-making capacity, either explicitly or in terms of insight or judgement, but it does not tend to undertake that consideration either with a presumption of capacity or of a recognition of the fundamentally restrictive process of denying a competent person their right to refuse treatment.

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[58] *YOB* [2015] VMHT 124.

[59] *WYV* [2014] VMHT 30.

VIII. DISCUSSION

On the basis of the arguments put forward in the first section, the Tribunal is obliged to carefully assess the patient's decision-making capacity when applying the least restrictive criterion. The first study found that a large majority of the Tribunals that heard these cases failed in that obligation. Even if the assertion that the Tribunal *should* be assessing the decision-making capacity of these patients is not accepted, there is reason to be concerned about the apparent diversity of approaches found when the reasoning set out in the statements is reviewed. These results suggest that there is no clear or coherent approach to this issue.

The second study confirms this, but also found that that while capacity is often considered by the Tribunal, and as part of the least restrictive criterion, it is not being considered in a way that is protective of a person's right to competently refuse treatment, but in a way that promotes what Gostin and Gable have called 'the myth of incompetency'.[60] They write that 'Competency is not an all or nothing proposition. It is tied to specific services, decisions, or functions.' When a person's capacity is used as a determination that a person has a mental illness, or as evidence that they need treatment for a mental illness, the link between the capacity to make the decision and the actual decision is lost. While the idea that capacity is intrinsic to mental illness is a long-standing assumption in philosophical debates,[61] Gostin and Gable write that 'Policies that assume a constant state of incompetency or impute a finding of incompetency in one area to apply to all other areas of decision making misunderstand mental disability and violate human rights standards.'[62]

While the Tribunal has not regularly assessed a person's capacity to determine if their competent refusal should be overborn, it has regularly considered insight, poor judgement and capacity in order to determine if a person is mentally ill or if treatment is required to prevent serious harm. This apparent assumption that a loss of capacity is inherently linked to mental illness is not defensible, and is at odds with the principles of the Act and therefore the intention of Parliament.

VIII. LIMITATIONS

The methodology of the both studies contain a number of issues that urge caution in interpretation. There is an element of sampling bias, in that the Tribunal only publishes statements of reasons in a limited number of cases, such as where a statement of reasons is requested. It is likely that statements will be requested in cases where one of the parties to the hearing disputes, or is at least troubled by, the outcome. The published cases represent only a fraction of all cases that the Tribunal determines and it is unlikely that they comprise a representative sample of all the cases heard. As noted above, treatment orders were made in only 65% of published statements of reasons examined in the second study, orders are actually made in around 94% of hearings for

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[60] Lawrence O Gostin and Lance Gable, 'Global Mental Health: Changing Norms, Constant Rights' (2008) 9(1) *Georgetown Journal of International Affairs* 83, 84.

[61] Gerben Meynen, 'Free Will and Mental Disorder: Exploring the Relationship' (2010) 31(6) *Theoretical Medicine and Bioethics* 429.

[62] Gostin and Gable, above n 60, 84.

treatment orders.[63] Similarly, of the total hearings with published statements of reasons examined in the second study, 66% had legal representation, while the actual percentage of hearings with legal representation is closer to 18%.[64]

Compounding the sampling issue, statements of reasons are reserved in that they are written at some point after the actual hearing and are constructed using contemporaneous brief handwritten notes and recordings of the hearing. While the clearest indicators that a consideration of the patient's decision-making capacity was conducted would be an explicit mention of the same or clear reference to the elements of decision-making capacity, it is important to recognise for the purposes of this exercise that the Tribunal may have considered this issue at the hearing without either of these clear indicators ending up in the published statement of reasons.

It is also inevitable that there will be an element of subjectivity involved in the allocation of some of the cases into groups, or the process of thematic analysis. While efforts were made to make the categories and themes as reliable and valid as possible, this is an inherently subjective process. Even using text queries, as in the second study, only reduces this factor, as longer statements of reasons will necessarily have more words in them, and will generate more returns, and the process of removing irrelevant returns will be as subjective as group or thematic allocation. The statements of reasons were not written with the intention of being thematically analysed, and considerations are often recorded in unrelated sections. This reduces the reliability of findings that certain aspects of capacity were considered in relation to certain criteria.

Despite this, these statements of reasons provide a valuable insight into the decision-making process of the Tribunal, and the two studies, undertaken in isolation and by unrelated researchers from different professional backgrounds, produced largely consistent results.

VIX CONCLUSION

Both authors have argued elsewhere for a capacity criterion which would restore the right of people with a mental illness to competently refuse treatment.[65] The current Victorian Act does not have an explicit capacity criterion, however the arguments laid out in this paper make it clear that given the fundamentally restrictive and discriminatory nature of denying this right, it should only be breached in a limited number of cases.

The two studies presented in this paper suggest that there is reason to believe that when applying probably the most important of the Act's protections of the rights of people with mental illness, the Tribunal is frequently not taking proper account of whether or not the patient is competently refusing the proposed treatment. In addition,

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[63] Victorian Mental Health Tribunal, 'Performance against Key Performance Indicators - 1 January to 31 March 2016' <http://www.mht.vic.gov.au/wp-content/uploads/2016/04/Performance-against-KPIs-January-to-March-2016.pdf>.

[64] Victorian Mental Health Tribunal, 'Mental Health Tribunal Annual Report 2014-15'. <http://www.mht.vic.gov.au/forms-and-publication/mental-health-tribunal-annual-reports-2/>.

[65] Ryan, above n 3; Maylea and Hirsch, above n 19.

the Tribunal is using evidence of a lack of decision-making capacity, closely tied to notions of judgement and insight, as indication that a person meets other criteria. This, along with the heterogeneity of the Tribunal's approach to this issue, should be cause for concern.

WHAT MAKES A 'GOOD' CONFERENCE FROM A SERVICE USER PERSPECTIVE?

SARAH GORDON AND KRIS GLEDHILL[*]

I. INTRODUCTION

This article started with a question from one academic wearing an editor's hat to another academic wearing an academic service user's hat[1]: conversing about a conference both had attended, the question asked was about the features that make conferences 'good' from a service user perspective. The question led to the comments that form Part II of this article. We then decided that we should combine resources and examine what the Convention on the Rights of Persons with Disabilities 2006 (CRPD)[2] has to say about the matter, identifying the normative framework of rights in the context of academic conferences that belong to those who attend in the context of experiencing psychosocial/mental impairment which in interaction with attitudinal and environmental barriers cause them to experience disability; and the corresponding obligations on conference organisers and/or those who regulate the situation and so might be required to impose obligations on conference organisers. This material, in Part III, is followed by some final reflections and thoughts as to good practice.

The context in which our arguments are framed is academic conferences on mental health and mental capacity law. Although our reference to 'service user' is therefore limited, some of our contentions can no doubt be applied to people experiencing other forms of disability and to conferences of a different type. These wider points are not a concentration in this article, but only because it was conceived and written with a more specific focus. Naturally, we are not suggesting that persons experiencing psychosocial or intellectual disabilities will only be interested in conferences on mental health and mental capacity matters, or that people experiencing other forms of disability will not have an interest in such conferences.

II. INITIAL COMMENTS

When Kris first asked me to write something on this topic I felt a bit indignant – what makes you think it would be any different to what you think makes a 'good' conference – presentations that provide new knowledge and/or perspectives on existing knowledge that are delivered well, and engagement with others, resulting in personal development through learning, reflection and networking. Having gotten over my initial indignation, I came to appreciate that maybe there are some matters concerning conferences that

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[1] 'Service user' is the term primarily used, throughout the present article, to describe people with personal experience of mental distress. This is for no other reason than it is the self-titled descriptor of one of the authors; and for many others in similar roles internationally at the present time. It is acknowledged that language itself is a matter of inclusion and a wide range of preferred self-descriptors exist.

[2] (United Nations [UN]) 2515 UNTS 3, UN Doc A/RES/61/106, Annex, GAOR 61st Session Supp 49, 65. (Adopted) 13 Dec 2006, (Opened For Signature) 30 Mar 2007, [Entered Into Force] 3 May 2008.

are particularly important from a service user perspective and that ought to be discussed.

A. Inclusion/exclusion

Recently I was involved in some research into the concepts of social inclusion and exclusion – as they relate to discrimination particularly – from the subjective and cross-cultural perspectives of people who experience mental distress in Aotearoa/New Zealand.[3] As a subjective phenomenon, social exclusion is the sense of “Otherness”, as if one is an alien. Whereas, the subjective phenomenon of social inclusion is feeling you are exactly where you should be, with the people who you should be with, and as the person you really are. This resonated with me in terms of the present article. Generally at conferences I do feel the sense of being ‘other’. However, I have now had the opportunity to attend a number of service user conferences, namely the Nutters conference which was held in New Zealand in 2006 (although I was initially loathe to go because I don’t like the term ‘nutter’) and the service user academia symposiums;[4] and I can’t communicate it any better than by saying that at those I feel I am exactly where I should be, with the people who I should be with, and as the person I really am.

Does that mean that we are unable to come together to conference in a way that is inclusive of all of us? I hope not but there is work still to be done, with some conferences requiring more work than others.

B. Nothing about us without us

Not long after I started in my first service user role – consumer advisor – I attended a mental health service conference in 1998. I think there may have been three of us coming from a service user perspective who attended. We went to everything, cringed a lot, didn’t say anything and engaged with no-one. The mantra of ‘nothing about us without us’ applies equally to conferences as it does to anything else concerning mental health. What’s more, that must extend to all aspects of the conference in order to be meaningful – organising committees, key-note and concurrent session presentations, posters, attendees, panellists.

Some conferences responded to the mantra of ‘nothing about us without us’ by facilitating a critical mass of service users to be in attendance. In some situations one may have been forgiven for thinking that a bus had been taken around all the local inpatient units to collect all the service users for a day trip. This practice seemed to overlook the importance of the ‘advisor’, ‘activist’, ‘worker’, ‘academic’ part of the role

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[3] Gordon, S., Davey, S., Waa, A., Tiatia, R., & Waaka, T. (In press). *Aotearoa/New Zealand: Social Inclusion and Exclusion, stigma and discrimination, and the experience of mental distress.* Auckland: Mental Health Foundation.

[4] This event originated in Auckland in 2011 and has subsequently been held annually via collaborations between universities in Australia and New Zealand. This symposium is for service users holding academic, education or professional development positions or aspiring to do so, and those (usually non-service users such as health professional academics and carers) who promote, support and advocate for these roles in academia and service settings.

description. Often these masses were visibly unwell and/or bombed out on medication and would spend the day either smoking or eating. In my opinion, this was not meaningful or respectful involvement for those service users in attendance, apart from perhaps in terms of a good feed and peer socialisation, or for others in attendance.

'Consumer days' were initially another popular way to involve service users at conferences. In my experience these were a mixed bag. Often they were facilitated more as a therapy session or an opportunity to spend hours debating the language we used to refer to ourselves, which whilst important, did get rather tiresome. In my opinion a good 'consumer day' is run similarly to any other professional body meeting where you discuss the issues and opportunities facing the ***work*** that you do. Of course, it is important that there is then provision for that information to be shared with the wider constituency.

Nowadays, I think many conferences do encourage and support the engagement of service user advisors, activists, workers, and academics in a manner that certainly has the potential to facilitate meaningful involvement. However, one of the things that has struck me recently is that there often remains an element of segregation, particularly in terms of service users engaging with service users, and others engaging with others, including by way of attendance at presentations – service users go to service user presentations, others go to what I perceive them to believe are the 'real' presentations. I think this could be partly addressed by having service-user presentation only streams.

C. Experiential-based knowledge

In terms of new knowledge and/or perspectives on existing knowledge, lived experience needs to be valued; and the lack of appreciation for that value is, in my opinion, the biggest barrier to 'good' conferences from a service user perspective. I find this perplexing. Perhaps it is a confounding of favourable perspectives on my part but the presentations people most often cite as having had the most immediate and lasting impact are those based on personal experience. Obviously not all personal experience based presentations have this level of impact. Like most things, there is an art to crafting and delivering such presentations. It is not simply a matter of sharing your story. Experience-based presentations must be tailored and relevant to the focus of the conference, its theme and audience. Often these presentations involve contesting 'dominant' paradigms and it is important that that is done in such a way that the audience will be receptive to (e.g. challenging but not attacking). It is also important to identify how the personal experience being shared applies in terms of new knowledge and/or perspectives on existing knowledge. Sometimes I feel presenters get distracted or daunted and feel the need to play-down their personal experience and come from a more 'academic' or traditional knowledge focused perspective. I can understand this but it is vitally important that if our role is to deliver a service user perspective, then that requires us to maintain a focus on the import and value of experiential-based knowledge. It is not a good idea to craft and deliver your presentation when unwell: been there, done that, got the stunned audience reaction to prove it. This can be difficult to manage if you get unwell in the intervening period between acceptance and delivery of a presentation however, this is no different to anyone else – there are a number of reasons why people are unable to fulfil their commitments on the day and good conferences should have contingencies in place. At the service user symposium we have a couple of extra presentations on stand-by.

D. A recent experience

Some 18 years after I attended my first conference in a service user capacity, I was stunned when in 2016 I attended a conference that completely and utterly flew in the face of ‘nothing about us without us’. To my knowledge there were only two people from a service user perspective in attendance and I was the only one that presented to the 20 or so people – out of the 200 in attendance – that chose the service user option. Admittedly I wasn’t that well going in (note to self: take own advice) and I am not great at small talk at the best of times and so my sense of being ‘other’ was exacerbated until acute alienation set-in and grew into full blown paranoia – I even thought the conference organising company didn’t want me there! I spent the majority of the conference in my room and most definitely did not attend the conference dinner. However, on the final day of the conference I had to check out of my room in the morning – by that time I was exhibiting some rather bizarre behaviour. Where is the quiet room when you need it? Well, definitely not here. So, I went to the hotel bar, wrapped my coat around my head, and started rocking. And then something extraordinary happened – the hotel staff inquired as to what they could do to help me; they turned the music down, they bought me tissues and a hot lemon, ginger and honey drink, they asked if I would be most helped by them sitting with me or leaving me alone, they attempted to change my flight so I could get home sooner. The irony: 200 psychiatrists one level above discussing the intricacies of disorders, diagnoses and medications whilst the basics of human kindness and compassion were being extended to me to support me out and away from one of the worst examples of doing nothing about us with us that I have ever encountered. I suppose the lesson being that a ‘good’ conference from a service user perspective is not just an academic exercise, it extends to being and keeping safe.

The remainder of this article focuses on human rights imperatives that support inclusive conferences and a series of suggestions and guidance that could transform this type of conference experience from being exclusionary and unsafe, to being inclusionary and safe for service users and of benefit to all.

III. THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES 2006

The human rights framework that has developed over the last 70 years provides a legal obligation that supplements the moral force and simple decency of conferences being designed to be inclusive. At the same time, the existence of a framework that brings with it legal obligations, provides an easier justification for why an approach should be adopted: ‘because it’s the law’ is a simple response to anyone who might doubt the sense of something. The framework is one that matures, and has seen the bringing into force of specific protections for persons with experience of disabilities. In this part, we set out first the place of non-discrimination as a core component of the human rights regime, then outline both the core principles behind the CRPD and specific rights it contains that, together, allow for the contention that creating a ‘good’ conference for service users is a matter of legal obligation.

A. Inclusivity as a part of non-discrimination: introduction

We are both based in Aotearoa New Zealand, where conferences and public events are invariably opened with te reo Māori speeches and songs. But New Zealand sign language – also an official language – is present less regularly. However, s 7 of the New Zealand Sign Language Act 2006 provides a right for parties, their representatives and members of the tribunal to use sign language in court proceedings. Naturally, there is a consequence to this, namely that there must be interpretation.[5]

The official recognition of sign language reflects an ethos of inclusivity backed by a legal framework, and is called for regularly by the Committee on the Rights of Persons with Disabilities,[6] the body established under article 34 of the CRPD to carry out various functions, namely considering reports from states as to the progress in their obligations to put the Convention into effect (articles 35 and 36), reporting to the UN and making suggestions and recommendations (article 39), and, in relation to states that have signed the Optional Protocol,[7] considering complaints. At the time of writing, the Committee has issued a few decisions on complaints, four general recommendations about the meaning of aspects of the Convention, and considered reports from a significant number of countries. This allows a growing confidence as to how the Convention will be interpreted.

The context of the Convention is that it is part of the UN's human rights regime, which centres around the International Bill of Rights, namely the Universal Declaration of Human Rights 1948 (UDHR),[8] the International Covenant on Economic, Social and Cultural Rights 1966 (ICESCR)[9] and the International Covenant on Civil and Political Rights 1966 (ICCPR).[10] The motif of equality is a core standard: the UDHR opens with

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[5] Te Ture mō Te Reo Māori 2016, the Māori Language Act 2016, confirms (under section 5) the status of the Māori language as an official language of New Zealand and the right (under section 7) to use it in legal proceedings.

[6] This is discussed below.

[7] Optional Protocol to the Convention on the Rights of Persons with Disabilities (United Nations [UN]) 2518 UNTS 283, UN Doc A/61/611, Annex I, GAOR 61st Session Supp 49 vol 1, 80, (Adopted) 13 December 2006), (Opened for signature) 30 March 2007 [Entered Into Force] 3 May 2008.

[8] (United Nations [UN]) UN Doc A/810, 71, UN Doc A/RES/217(III) A, GAOR 3rd Session Part I, 71 (Adopted) 10 December 1948 the text is available at http://www.un.org/en/universal-declaration-human-rights/index.html. See also Charter of the United Nations (done at San Francisco, United States, on 26th June 1945) (United Nations [UN]) 892 UNTS 119, 59 Stat 1031, TS 993, 3 Bevans 1153, 145 BSP 805, (Adopted) 26 June 1945, (Signed) 26 June 1945, [Entered Into Force] 24 October 1945, available at; http://www.un.org/en/charter-united-nations/index.html. Its preamble refers to the determination of the states "to reaffirm faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women …" The purposes of the UN are set in article 1 as including ".... To achieve international cooperation in … promoting respect for human rights and for fundamental freedoms for all without distinction as to race, sex, language, or religion …" Noticeably, the grounds on which discrimination is improper is more limited and does not have the catch-all reference to "other status" that appears in the UDHR a short time later.

[9] (United Nations [UN]) 993 UNTS 3, CTS 1976/46, S Exec Doc D, 95-2 (1978), GAOR 21st Session Supp 16, 49, UN Doc A/6316, UN Doc A/RES/21/2200, (Adopted) 16 Dec 1966, (Signed) 16 Dec 1966, [Entered Into Force] 3 Jan 1976.

[10] (United Nations [UN]) 999 UNTS 171, UN Doc A/6316, UN Doc A/RES/2200(XXI), Annex, UN Reg No I-14668, (Signed) 16 December 1966, [Entered Into Force] 23 March 1976.

the indication in its article 1 that “All human beings are born free and equal in dignity and rights”, and makes the point in its article 2 that the rights it goes on to set out are to be enjoyed by all “without distinction of any kind” based on the status of the person. In short, the recognition of equality and prohibition of discrimination are features of the first two articles of this opening document of the International Bill of Rights. Article 7 supplements this with the indication that:

> All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

Article 2(2) of the ICESCR specifies that the rights it contains have to be guaranteed “without discrimination of any kind” arising from status; article 2(1) of the ICCPR is to similar effect, albeit that it refers to the absence of “distinction” rather than referring to “discrimination”. The ICCPR contains the equivalent of article 7 of the UDHR: its article 26 notes:

> All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

In short, protection against discrimination in relation to anything set out in law is itself a civil and political right. The need for “equal and effective protection” is to be noted.

Supplemental treaties have been developed that explain the application of this and the other substantive standards in the context of various groups of people who have often been subject to discriminatory treatment on account of various features (race, gender, youth, migrant worker status and disability). The CRPD is designed to counter, as it identifies in its preamble, the fact that, despite the standards set out in these human rights instruments “persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world”.[11] It does not seek to define ‘disability’, noting that it is “an evolving concept … that 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”.[12] However, article 1 of the CRPD confirms that included within the Convention are “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder

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[11] Convention on the Rights of Persons with Disabilities (United Nations [UN]) 2515 UNTS 3, UN Doc A/RES/61/106, Annex, GAOR 61st Session Supp 49, 65. (Adopted) 13 Dec 2006, (Opened For Signature) 30 Mar 2007, [Entered Into Force] 3 May 2008, preamble para (k). A Handbook for Parliamentarians on the Convention, *From Exclusion to Equality, Realizing the rights of persons with disabilities*, issued by the High Commissioner for Human Rights, the Department of Economic and Social Affairs of the UN, and the Inter-Parliamentary Union, https://www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities.html, last accessed 19 July 2017 - contains the comments that “Persons with disabilities remain amongst the most marginalized in every society. While the international human rights framework has changed lives everywhere, persons with disabilities have not reaped the same benefits” (Foreword, piii).

[12] Convention on the Rights of Persons with Disabilities 2006 preamble para (e).

their full and effective participation in society on an equal basis with others".

The specific problem of attitudes is summed up in a Handbook for Parliamentarians on the Convention, namely that:[13]

> Persons with disabilities are still primarily viewed as "objects" of welfare or medical treatment rather than "holders" of rights. The decision to add a universal human rights instrument specific to persons with disabilities was borne of the fact that, despite being theoretically entitled to all human rights, persons with disabilities are still, in practice, denied those basic rights and fundamental freedoms that most people take for granted.

Accordingly, note the authors:[14]

> The Convention is a complement to existing international human rights treaties. It does not recognize any new human rights of persons with disabilities, but rather clarifies the obligations and legal duties of States to respect and ensure the equal enjoyment of all human rights by all persons with disabilities.

This reference to the lack of new rights is an accurate but understated summary of the aims of the Convention. In particular, since rights are concepts that have meaning, a change that elucidates a meaning more accurately may properly be said to create a new concept. Moreover, since the human rights framework is designed to be "practical and effective",[15] the high-level statements of rights found in the overarching International Bill of Rights will often require more specific elucidation. Treaties such as to the CRPD provide examples of what this specificity means. Hence, as Harpur has commented:[16]

> ... the CRPD does not merely re-state existing human rights. The CRPD re-states existing rights and then creates incidental rights to ensure that existing rights are realized. Through this process existing rights are provided greater clarity, which provides disability advocates and scholars with a powerful tool to hold states accountable.

In fact, the power of the CRPD is that it compels a shift in attitudes that secure what has been described as a paradigm shift. Glen, speaking in the context of guardianship arrangements for people with intellectual disabilities, has noted that the concept of a paradigm shift, involving a development that alters or reorients a historical

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[13] *From Exclusion to Equality, Realizing the rights of persons with disabilities*, above n 10, p4.

[14] *From Exclusion to Equality, Realizing the rights of persons with disabilities*, above n 10, p5.

[15] This phrase is used by the European Court of Human Rights in relation to its decisions under the European Convention on Human Rights, Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols No 11 and 14 (Council of Europe) 213 UNTS 222, ETS No 5, UN Reg No I-2889, (Opened For Signature) 4 November 1950 [Entered Into Force] 3 September 1953 [Amended] 1 June 2010; available at http://conventions.coe.int/treaty/en/treaties/html/005.htm (last accessed 17 August 2017). For example, in *Airey v Ireland*, Merits, App No 6289/73, A/32, IHRL 23 (ECHR 1979), [1979] ECHR 3, (1980) 2 EHRR 305, [1979] EuGRZ 626, 9th October 1979, European Court of Human Rights [ECHR], it commented at [24], "The Convention is intended to guarantee not rights that are theoretical or illusory but rights that are practical and effective". The context was the Court's conclusion that legal aid had to be made available if it was necessary to secure a fair trial in a civil matter even though the Convention is express as to legal aid only in relation to criminal charges.

[16] Paul Harpur "Embracing the new disability rights paradigm: the importance of the Convention on the Rights of Persons with Disabilities" (2012) 27:1 Disability and Society 1, 2.

perspective,[17] is a "framework" that is "helpful in moving us from what has become a comfort zone to a new way of thinking about people with intellectual disabilities and their capacities".[18] The Committee on the Rights of Persons with Disabilities has endorsed the idea that there is a new paradigm in various Concluding Observations to states parties.[19] Accordingly, we turn to the rights of persons experiencing psycho-social/mental impairment, which in interaction with attitudinal and environmental barriers cause them to experience disability, who attend conferences to present or participate and suggest what they should be understood to mean. This involves first understanding the core obligation arising.

B. The core obligation under the CRPD

The basic general obligation undertaken by the CRPD in order to set right the ongoing failure to secure equality of enjoyment of rights, and thereby secure the new paradigm involved, is set out in article 4: "ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability".[20] The key question of what amounts to "discrimination on the basis of disability" is defined in article 2:

> "Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose *or effect* of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation. (Emphasis added.)

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[17] Kristin Booth Glen, "Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond" (2012) 44 Columbia Human Rights Law Review 93, 96-99; the phrase describing the concept is credited to Thomas S Kuhn *The Structure of Scientific Revolutions* (University of Chicago Press, Chicago, 1962.

[18] Kristin Booth Glen, "Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond" (2012) 44 Columbia Human Rights Law Review 93, 98. Kristin notes that the view of people with limited capacity being treated as objects of charity and placed under guardianship in their best interests was being replaced by a supported decision-making approach – an "emerging paradigm" which "challenges our perceptions and our understanding of when, how, and even *if* the state may intervene in a person's life".

[19] See the concluding observations on Belgium UN Doc CRPD/C/BEL/CO/1 (28 October 2014), para 17, dealing with the Committee's concerns as to inadequate steps to comply with the need for awareness-raising to comply with article 8: "The Committee is concerned that there is no sign that a paradigm shift has occurred following ratification of the Convention, whereby persons with disabilities are recognized as basic rights holders taking part in decisions affecting them and asserting their rights in society"; Slovakia UN Doc CRPD/C/SVK/CO/1 (17 May 2016), para 4, under the heading "Positive aspects": "The Committee welcomes the recognition of the paradigm shift required to realize the rights of persons with disabilities in the State party as well as the efforts to adopt a human rights-based approach to disability"; Cyprus UN Doc CRPD/C/CYP/CO/1 (8 May 2017), para 34(b), in the context of the Committee's concerns that article 12 was breached because of the failure to move from substituted decision-making processes, it recommended that Cyprus "Allocate adequate human, technical and financial resources to support the transformation from the present paradigm to a new paradigm that is in line with the Convention, and being guided by, inter alia, general comment No. 1 (2014)".

[20] It is to be noted that article 4.4 makes it plain that the Convention is not to be used as a justification for reducing the impact of any provisions of domestic law (or any other provisions of international law binding on the state) "which are more conducive to the realization of the rights of persons with disabilities"; nor can there be any restrictions on human rights that exist under the law, conventions, regulation or custom of domestic law on the basis that there is lesser protections guaranteed in the Convention.

The "denial of reasonable accommodation" is also defined in article 2 in the following terms:[21]

> "Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

The Convention sets out various specific obligations that supplement the general obligation to promote rights: states have to:

- "adopt all legislative, administrative and other measures" to implement the Convention (article 4.1(a)),
- take "all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities" (article 4.1(b)),[22]
- mainstream consideration of matters of disability by ensuring that the rights of persons with disabilities are taking into account "in all policies and programmes" (article 4.1(c)),
- ensure that all public bodies comply (article 4.1(d)),
- regulate to prevent private sector discrimination on the basis of disability (article 4.1(e)),[23]
- promote "universally designed goods, services, equipment and facilities" (article 4.1(f)), which picks up a further concept set out in article 2 – namely "Universal design", which is defined as "the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design";[24]
- promote research into and the availability of new assistive technologies (article 4.1(g)), and accessible information on technologies and support services (article 4.1(h)), and
- promote the training of those who work with people with disabilities as to what their rights entail (article 4.1(i)).

These features can be seen as examples of steps that have to be taken by the state to comply with the general principles behind the terms of the Convention, which are set out in its article 3 and are worth reproducing in full:

> (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
> (b) Non-discrimination;
> (c) Full and effective participation and inclusion in society;
> (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
> (e) Equality of opportunity;
> (f) Accessibility;
> (g) Equality between men and women;
> (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The focus is full integration and respect for autonomy, which may require additional consideration to overcome the impact of any disability or the perception of others as to

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[21] See also the concept of "Universal design", described below.

[22] This has to involve consultation with and the involvement of persons with disabilities: article 4.3.

[23] This reflects the concept of "horizontal effect", namely that breaches of rights caused by private persons or bodies can be the responsibility of the state if the latter has not handed down legislation or taken other measures within its powers to control private sector behaviour in order to safeguard rights.

[24] It is also made clear in article 2 that "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed".

its impact, so as to ensure true equality.

This account of the general features of the CRPD allows the following points to be made about its consequences in the specific context of conference organization. Firstly, in light of article 4.1(d) and (e), whether a conference is organised by a public or private sector body, the obligations that flow from the CRPD should apply. The state is under a duty to ensure that appropriate mechanisms are in place. Those who organise conferences, whether they are state-funded or entirely commercial, can voluntarily ensure respect for the rights of attendees who experience disability (which consequently may avoid the need for legislation) if that means there is no need for corrective state intervention.

Secondly, the core of ensuring non-discrimination includes ensuring that reasonable accommodation is made, since denial of reasonable accommodation amounts to discrimination on the basis of disability. In short, such proportionate and non-burdensome steps as can be taken to ensure that a conference can be enjoyed equally by persons with experience of disability must be taken: this will, naturally, turn on the facts, including the information available as to the needs of those with experience of disability who wish to attend a particular conference.

Thirdly, and in fact before one gets to the need for reasonable accommodation, there is the important concept of universal design, the definition of which is set out above and in the conference setting means the use of "environments, programmes and services" that can be used by all. Essentially, the starting question in terms of conference design, including the facilities at which the conference will be held, should be whether the arrangements are disability-friendly in that they can be used by all people, whether impaired or not. The obvious point to make, and the reason why universal design should be the opening motif, is that the greater the level of universal design, the less need there will be for separately-required reasonable accommodation. This reflects an important feature motivating the concept of universal design, namely that it prevents inclusion being a supplemental task, or one that puts the inclusion of persons who experience disabilities as something of an end-thought: this is self-evidently not an appropriate approach.

C. Relevant specific rights in the CRPD

Various of the specific rights that have to be guaranteed by virtue of the various provisions of article 4 (noted above) are of obvious relevance to the context of academic conferences: namely article 9 (accessibility), article 21 (freedom of information and access to information), and article 24 (education). It is important to understand to breadth of their coverage to appreciate their potential value; it is also important to read them together with the core obligation described above.

1. *Accessibility*

The right to accessibility in article 9 (and the supporting principle in article 3(f)) covers not just the physical environment and transport facilities (important though that is, including in the context of conferences, given that people have to get to an event and be able to get into lecture halls): it also covers "information and communications ... and ... other facilities and services open or provided to the public" (article 9(1)). The purpose of this is set out as "To enable persons with disabilities to ... participate fully in all aspects of life" (article 9(1)). Obviously, academic conferences are often linked to the promulgation of public of research, which is information and so within the coverage of article 9(1).

The state must ensure that practical effect is given to this by reason of article 9(2), which points to the need for monitoring, facilitation and promotion, including through the training of "stakeholders". When combined with the general obligation in article 4(1) to take steps to change laws and practices, this means that failures by those involved in conferences to meet the needs of accessibility should be dealt with by way of relevant regulation. Indeed, article 9(2)(b) requires the state to ensure that "private ... facilities and services which are open or provided to the public" take accessibility needs into account. Other relevant specific obligations set out in article 9(2) include the provision of relevant interpreters and intermediaries so as to facilitate accessibility. This obligation as to provision is state-wide, which will allow entities that arrange conferences (or other examples of relevant services within article 9) to hire them.

The Committee on the Rights of Persons with Disabilities has expanded upon the impact of article 9 in its General Comment No 2.[25] It makes the point that as "[a]ccessibility is related to groups, whereas reasonable accommodation is related to individuals", "the duty to provide accessibility is an ex ante duty" which does not turn on the receipt of a complaint of non-accessibility.[26] This means that there should be a review of relevant laws to ensure universal design and accessibility standards, backed up by sanctions for non-compliance.[27] Moreover, the Committee indicates that there should be accessibility action plans, together with monitoring mechanisms to ensure implementation.[28] The Committee thereby makes it clear, perhaps particularly through the requirement for sanctions, which might be achieved via regulatory criminal law, that it takes seriously the need to ensure that organisations take suitable steps to comply with this aspect of inclusivity as an aspect of non-discrimination. Conference organisers can take the necessary steps to ensure participation: or public welfare regulation to require it will

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[25] Committee on the Rights of Persons with Disabilities, General Comment No 2 (2014), Article 9: Accessibility [UN Doc CRPD/C/GC/2] (22 May 2014).

[26] (2014), Article 9: Accessibility [UN Doc CRPD/C/GC/2] (22 May 2014), para [25]. In para [26], it is stated that "The duty to provide reasonable accommodation is an *ex nunc* duty, which means that it is enforceable from the moment an individual with an impairment needs it in a given situation, for example, workplace or school, in order to enjoy her or his rights on an equal basis in a particular context".

[27] (2014), Article 9: Accessibility [UN Doc CRPD/C/GC/2] (22 May 2014), para [28]. Indeed, it is also suggested that denial of access should be defined as amounting to discrimination: para [29]. The need for sanctions or penalties as part of the monitoring process has been a regular feature of concluding observations issued since the General Comment: see, for example, the concluding observations on Mexico UN Doc CRPD/C/MEX/CO/1 (27 October 2014), para 20(b) and (e); Germany UN Doc CRPD/C/DEU/CO/1 (13 May 2015), para 22(a); Ethiopia UN Doc CRPD/C/ETH/CO/1 (4 November 2016), para 20; Cyprus UN Doc CRPD/C/CYP/CO/1 (8 May 2017), para 26. In relation to Kenya reference is made the need to implement regulations under its Persons with Disabilities Act No 14 of 2003 that include the making of "adjustment orders" for non-compliance: UN Doc CRPD/C/KEN/CO/1 (30 September 2015), para 18(b).

[28] (2014), Article 9: Accessibility [UN Doc CRPD/C/GC/2] (22 May 2014), para [33].

follow.

2. *Expression and Information*

Article 21 is the right to freedom of expression and opinion, and also the right of access to information. As such, it is phrased so as to include not just passing on views but also "the freedom to seek, receive ... information and ideas on an equal basis with others".[29] This cannot be construed other than as including a right to attend conferences (both as a speaker and as an audience member) on equal terms, and hence with the requirements of universal design and accessibility to assist at the group level and reasonable accommodation to facilitate the needs of any particular individual.

The text of article 21 gives further assistance as to what this should entail in practice. States must take "all appropriate measures" to ensure people with experience of disability can exercise the right on an equal basis and, as part of this must, respect the communication of choice of the person with experience of disability. This is also defined in article 2, in which it is noted that:

> Communication" includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology ...

In light of this, it is noted in article 21 that states have duties to provide public information in accessible formats and allow people with experience of disability to use their choice of communication in interactions with state machinery, but also are required to encourage the use of accessible formats in the mass media and by "private entities that provide services to the general public" (article 21(c)). Such specific references to the need for action by private entities reinforces the general point made above that the legal system has to be used to ensure that rights are respected within both the public and private sectors.

There is a specific obligation to both recognise and promote the use of signing (article 21(e)). In making recommendations for change as part of the concluding observations issued to states, the Committee on the Rights of Persons with Disabilities has regularly called for the recognition of sign language where it is not officially recognised, and for improvements in relation to its use in other instances, often in the form of additional training or funding to allow additional hiring of interpreters. Examples of calls for official recognition (which would no doubt prompt additional use and, naturally, empower users to remind others of its importance) include various wealthy nations such as Australia,[30] the Republic of Korea,[31] Italy,[32] and Canada (with a reference to both American and Quebec Sign Language to reflect the two main language cultures of the country).[33] In addition, there were instances where there was recognition but the law

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[29] In this regard, it follows the structure of its equivalent in the ICCPR, Article 19.2, which expressly includes both imparting information and receiving it.

[30] Concluding observations Australia UN Doc CRPD/C/AUS/CO/1 (21 October 2013), para 44.

[31] Concluding observations Republic of Korea UN Doc CRPD/C/KOR/CO/1 (29 October 2014), para 42.

[32] Concluding observations Italy UN Doc CRPD/C/ITA/CO/1 (6 October 2016), para 50.

[33] Concluding observations Canada UN Doc CRPD/C/CAN/CO/1 (8 May 2017), para 40.

was not properly implemented: this was recognised in the case of Costa Rica[34] and Croatia.[35] An interesting dynamic was noted in the context of Denmark, in relation to which there was a call for the recognition of Faroese sign language but also for people to have a right to use sign language even after a successful cochlear implant.[36]

As has been noted above, human rights should be made "practical and effective",[37] which in turn means that resources have to be in place to secure the implementation of a right. Hence, the Committee, whilst congratulating various countries for the recognition of the right to sign language nevertheless called for the taking of practical steps such as the provision of resources for training interpreters. Accordingly, for example, New Zealand was commended for recognising sign language as an official language and establishing a Sign Language Board to promote its use,[38] but was told that it needed to do more to promote the training and employment of sign language interpreters, particularly for Maori and Pacific peoples.[39] Similarly, the Czech Republic[40] and Ukraine[41] were congratulated for official recognition but reminded that that was not the sum total of the obligation: the Czech Republic was informed of the obligation to provide resources for the training and hiring of interpreters to give effect to the right to use sign language,[42] as was Ukraine.[43]

The clarity of the calls for ensuring participation for those who make use of signing can be seen as an instance of a more general need. In relation to various countries, the call made was a more general one for use to be made of accessible formats of communication, and particularly in relation to public information. For example, in the case of Brazil, the call made was more generally for "resources and training" to be provided to allow information aimed at the public to be published "in accessible formats and technologies" (and in timely fashion);[44] in relation to Colombia, it was noted that there was a need for relevant resources "to facilitate access to information in accessible modes, means and formats of communication";[45] and in the EU report, a reference to sign language was made in the context of it being one of the various "accessible languages, formats and technologies".[46] Other examples include Denmark, which was encouraged to promote "augmentative and alternative modes of communication that are accessible to people with intellectual and mental disabilities";[47] Cyprus, in relation to which it was noted that a right to use tactile communication would ensure its users

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[34] Concluding observations Costa Rica UN Doc CRPD/C/CRI/CO/1 (12 May 2014), para 42.

[35] Concluding observations Croatia UN Doc CRPD/C/HRV/CO/1 (15 May 2015), para 32.

[36] Concluding observations Denmark UN Doc CRPD/C/DEN/CO/1 (30 October 2014), para 45.

[37] See text to fn 14 above.

[38] Concluding observations New Zealand UN Doc CRPD/C/NZL/CO/1 (31 October 2014), para 4.

[39] ibid paras 42/44.

[40] Concluding observations Czech Republic UN Doc CRPD/C/CZE/CO/1 (15 May 2015), para 4.

[41] Concluding observations Ukraine UN Doc CRPD/C/UKR/CO/1 (2 October 2015), para 4(a).

[42] Concluding observations Czech Republic UN Doc CRPD/C/CZE/CO/1 (15 May 2015), para 42.

[43] Concluding observations Ukraine UN Doc CRPD/C/UKR/CO/1 (2 October 2015), para 39.

[44] Concluding observations Brazil UN Doc CRPD/C/BRA/CO/1 (29 September 2015), para 39.

[45] Concluding observations Colombia UN Doc CRPD/C/COL/CO/1 (30 September 2016), para 51. This was a report that did not mention sign language or Braille specifically: but clearly they are included within the more general description.

[46] Concluding observations EU UN Doc CRPD/C/EU/CO/1 (2 October 2015), para 55.

[47] Concluding observations Denmark UN Doc CRPD/C/DEN/CO/1 (30 October 2014), para 49.

"their participation and recognition in all spheres of life on an equal basis with others";[48] and Moldova, which was encouraged to use accessible formats for all public services, especially for children in inclusive education.[49]

The more general point of principle of which these are illustrations, is that the Committee wishes that states take seriously the obligation to ensure that information can be passed and received: the obvious consequence of this is that publicly accessible information has to be provided in a way that allows equal access to people who experience disability. This will include information for which a conference registration is necessary. Whilst this most obviously includes supplemental methods of communication for the hearing and vision-impaired, what is needed will depend on the nature of the impairment, and so if participation in a conference requires a supportive environment, that is what is mandated.

The link between article 9 and article 21 is noted by the Committee, which comments that, "Without access to information and communication, enjoyment of freedom of thought and expression and many other basic rights and freedoms for persons with disabilities may be seriously undermined and restricted".[50] In its concluding observations to Italy, the Committee makes specific reference to the need for the educational sector to ensure accessibility. It notes the need for an audit leading to an action plan:[51]

> to ensure the provision of live assistance and intermediaries, including guides, readers and professional sign language interpreters, and augmentative and alternative communication across all public sectors. In particular, augmentative and alternative communication must be provided free of charge in the education sector.

Along similar lines, in its concluding observations relating to Jordan, the Committee expressed its concern about the difficulties of access to various aspects of life owing to limitations in communication,[52] and so recommended that various steps be taken, including:

> the provision of live assistance, intermediaries, guides, readers, accessible information kiosks, ticket vending machines, websites, mobile applications and professional and certified sign language interpreters to facilitate access to public buildings, facilities, transportation and information and communication services...

This language is suitable to cover the provision of information in the form of conference lectures and seminars.

3. *Education*

The final right of obvious application to academic conferences is the right to education,

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[48] Concluding observations Cyprus UN Doc CRPD/C/CYP/CO/1 (8 May 2017), para 46.

[49] Concluding observations Moldova UN Doc CRPD/C/MDA/CO/1 (18 May 2017), para 41(c).

[50] Committee on the Rights of Persons with Disabilities, General Comment No 2, CRPD/C/GC/2, 22 May 2014, para [21].

[51] Concluding observations to Italy UN Doc CRPD/C/ITA/CO/1 (6 October 2016), para 24.

[52] Concluding observations to Jordan UN Doc CRPD/C/JOR/CO/1 (15 May 2017), para 21.

as set out in article 24.[53] This expressly includes, in article 24.1, "an inclusive education system at all levels and life-long learning". The importance of the right to education is noted, including such matters as developing human potential and personality, self-worth and dignity, and enabling effective participation in society. Article 24(5) deals more specifically with post-school education, indicating that:

> States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

Academic conferences should be considered to constitute part of lifelong learning. As has been noted already in relation to access rights, this obligation on states is to be combined with the general obligation of enforcement and as such, means that the failure of providers of lifelong learning to adopt relevant policies should lead to the imposition of regulation.

The Committee on the Rights of Persons with Disabilities has emphasised the value of the right to education in its fourth General Comment.[54] It comments that the changed perception of people who experience disabilities (as rights holders rather than as recipients of welfare) means that there is a recognised right to education, which has to be inclusive to ensure that people with experience of disability receive education of the same quality:[55] this seems obvious when one recalls the unimpressive history of the separate but equal motif in the context of racial discrimination.

The core components of inclusive education are enunciated by the Committee and include:[56]

> (e) Respect for and value of diversity: all members of the learning community are equally welcome and must be shown respect for diversity … All students must feel valued, respected, included and listened to …
> (f) A learning-friendly environment: inclusive learning environments are accessible environments where everyone feels safe, supported, stimulated and able to express themselves …

In relation to the right to tertiary and lifelong learning set out in Article 24(5), the

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[53] Note should also be taken of article 29, the right to participation in political and public life, which will also include matters of law reform; academic conferences may include papers relating to law reform in the area of law that particularly affects persons who experience disability. This article will reinforce the need to steps to ensure equal participation in such a situation.

[54] Committee on the Rights of Persons with Disabilities, General Comment No 4 on the right to inclusive education, CRPD/C/GC/4, 25 November 2016.

[55] Committee on the Rights of Persons with Disabilities, General Comment No 4 on the right to inclusive education, CRPD/C/GC/4, 25 November 2016, paras [1]-[3]. There is an older UNESCO Convention against Discrimination in Education (United Nations Educational, Scientific and Cultural Organization [UNESCO]) 429 UNTS 93, UN Reg No I-6193, (Adopted) 14 December 1960, (Signed) 14 December 1960, [Entered Into Force] 22 May 1962, which New Zealand ratified in 1963: it prevents separate systems or institutions for different groups save for permitting single sex schools and ones based on religion or language (Articles 1(c) and 2).

[56] Committee on the Rights of Persons with Disabilities, General Comment No 4 on the right to inclusive education, CRPD/C/GC/4, 25 November 2016, para [12].

Committee notes:[57]

> Attitudinal, physical, linguistic, communication, financial, legal and other barriers to education at these levels must be identified and removed in order to ensure equal access. Reasonable accommodation must be provided to ensure that persons with disabilities do not face discrimination. States parties should consider taking affirmative action measures in tertiary education in favour of learners with disabilities.

Just as there is a link between articles 9 and 21, so there is a link between articles 21 and 24. In particular, article 24(3) requires the development of suitable modes of communication in the sphere of education, with specific reference being made to the need to facilitate the learning of "Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills", as well as sign language and making use of "peer support and mentoring". Article 24(4) in turn recognises that this requires teachers who are able to use these modes of communication and have disability awareness training.[58] Article 8, which requires awareness-raising as to the rights and abilities of people with experience of disability, is worth noting. In its concluding observations to El Salvador, the Committee's recommendations included "promoting disability education as a cross-cutting theme in university courses".[59]

Reference can also be made to the UN's Sustainable Development Goals, as adopted by the General Assembly in September 2015.[60] The vision behind the 17 SDGs and accompanying 169 targets includes a vision of, inter alia, a "world with equitable and universal access to quality education at all levels",[61] and a commitment to "inclusive and equitable quality education at all levels" and to "life-long learning opportunities", including for people who experience disabilities, which are viewed as having utilitarian skills-building purposes but also as reflecting participation in society.[62]

Goal 4 is "Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all", and the specific elements of this include, in Target 4.5:

> By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations.

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[57] Committee on the Rights of Persons with Disabilities, General Comment No 4 on the right to inclusive education, CRPD/C/GC/4, 25 November 2016, para [38].

[58] Accordingly, in the concluding observations to Australia UN Doc CRPD/C/AUS/CO/1 (21 October 2013), para 44, relating to article 21 freedom of expression, the Committee noted that it was necessary to facilitate alternative modes of communication in light of articles 24(3) (education) and also 29(b) (participation in public life). Going further, in the concluding observations to Azerbaijan UN Doc CRPD/C/AZE/CO/1 (12 May 2014), para 35, a similar point was made in the comments under article 21 but with a citation of article 9 as well as articles 24(3) and 29(b). Note also that in the concluding observations to the Dominican Republic UN Doc CRPD/C/DOM/CO/1 (8 May 2015), para 42, the Committee encouraged the use of sign language in educational institutions, starting in primary institutions.

[59] Concluding observations El Salvador UN Doc CRPD/C/SLV/CO/1 (8 October 2013, para 22.

[60] UN General Assembly *Transforming our world: the 2030 Agenda for Sustainable Development* A/Res/70/1 (25 September 2015).

[61] ibid para [7].

[62] ibid para [25].

Supplementing this, Goal 4(a) refers to the building and upgrading of "inclusive and effective learning environments for all". UNESCO, working with other bodies, has developed a programme for the implementation of Goal 4, the Incheon Declaration and Framework for Action.[63] It builds on past commitments which have some references to education and people who experience disability. The World Declaration on Education for All and Framework for Action to Meet Basic Learning Needs,[64] from 1990, set out the need for equity in Article III of the Declaration, including in Article III.5:

> The learning needs of the disabled demand special attention. Steps need to be taken to provide equal access to education to every category of disabled persons as an integral part of the education system.

This led to the Dakar Framework for Action of 2000,[65] and the Muscat Agreement of 2014.[66] The latter set the provision for all of equitable and inclusive education (including lifelong learning) as the target for 2030,[67] to which fuller effect is given through the Incheon Declaration. It includes the indication in its paragraph 7 that:

> **Inclusion and equity** in and through education is the cornerstone of a transformative education agenda, and we therefore commit to addressing all forms of exclusion and marginalization, disparities and inequalities in access, participation and learning outcomes. No education target should be considered met unless met by all. We therefore commit to making the necessary changes in education policies and focusing our efforts on the most disadvantaged, especially those with disabilities, to ensure that no one is left behind.

As with the rights already discussed, there is supplemental supporting material in Concluding Observations issued to states. For example, the Committee commended Austria for offering sign language interpretation at the tertiary level, but also expressed its disappointment that there had only been 13 students by the time the matter was considered and only 3 had graduated and recommended that more efforts be made;[68] Ecuador was encouraged to "Step up efforts to implement models of inclusive education for persons with disabilities at the university level by encouraging adaptations to the curriculum and premises of universities for the various courses they offer" as a response to the concern that the lack of adjustments meant that there was limited access;[69] Germany was encouraged to "[e]nsure that reasonable accommodation is provided at all levels of education and that the right to such accommodation is legally enforceable and justiciable before the courts" and to ensure that sign language was available in all

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[63] UNESCO, Education 2030 – Incheon Declaration and Framework for Action, available at http://en.unesco.org/education2030-sdg4.

[64] UNESCO, World Declaration on Education for All and Framework for Action to Meet Basic Learning Needs, the outcome of the World Conference on Education for All – *Meeting Basic Learning Needs* at Jomtien, Thailand, 5-9 March 1990, UNESCO, Paris, 1990.

[65] UNESCO, The Dakar Framework for Action – Education for All: Meeting Our Collective Commitments, the outcome of the World Education Forum, Dakar, Senegal, 26-28 April 2000 (and several regional meetings), UNESCO, Paris, 2000. Specific reference to the needs of disabled people is made in declarations from the regional meetings.

[66] UNESCO, The GEM Final Statement – The Muscat Agreement, outcome of the Global Education for All Meeting, Muscat, Oman, 12-14 May 2014.

[67] ibid, para 10.

[68] Concluding observations Austria UN Doc CRPD/C/AUT/CO/1 (30 September 2013), paras 41 and 43.

[69] Concluding observations Ecuador UN Doc CRPD/C/ECU/CO/1 (27 October 2014), para 37.

institutions, “including at the post-doctoral level”;[70] Croatia was encouraged to provide access at the tertiary level and provide reasonable accommodation, with the additional recommendation to establish “the principle that exclusionary and segregated education is discriminatory”;[71] and Italy was encouraged to ensure equal access and also “build and upgrade education facilities that are disability sensitive and safe”.[72]

The recommendations in relation to Chile provide a good example of a comprehensive approach. It was encouraged to take various steps to respond to concerns about “the lack of action by government authorities to promote inclusive higher education”,[73] in addition to the general point relating to the link with the SDGs, namely:

> “(a) Implement a plan for transitioning towards inclusive education at all levels up to higher education, which provides for the training of teachers, the roll-out of comprehensive awareness-raising campaigns and the promotion of a culture of diversity;
> (b) Provide personalized instruction and the necessary support and resources, such as Braille and sign language, to foster inclusion, in particular of students with intellectual or psychosocial disabilities;
> (c) Ensure the accessibility of higher education institutions, including by facilitating reasonable accommodations in the admissions process and all other aspects of higher education; ...”[74]

The Committee has indicated that the Convention approach to the right to education, picking up the paradigm changing motif, involves a “transformation in culture, policy and practice”.[75] This may be over-stating it, since it will often be a matter that involves just some basic thought about inclusivity that will help to ensure that a conference is able to meet this need. Mainstreaming of a disability perspective, invariably by ensuring the involvement of people with experience of disability in the process of organising a conference and starting from the principles of universal design and, where necessary, reasonable accommodation, will provide an easy method of compliance with the obligations that exist.

IV. SUGGESTIONS AND GUIDANCE

The material in Part III indicates that persons who experience psychosocial/mental impairment which in interaction with attitudinal and environmental barriers cause them to experience disability, whether acting as academics or members of the public, have the right to attend academic conferences on mental health and mental capacity law on the same terms as those without that experience. It arises from the width of the right to access, which extends to information; the right to impart and receive information; the right to education, including lifelong education; and the more general right to equal treatment, the elements of which include the use of universal design and reasonable accommodation. These are elements of the inclusivity programme that is key to recognising the rights of people with experience of disability to full participation in life.

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[70] Concluding observations Germany UN Doc CRPD/C/DEU/CO/1 (13 May 2015), para 46.

[71] Concluding observations on the initial report of Croatia UN Doc CRPD/C/HRV/CO/1 (15 May 2015), para 36.

[72] Concluding observations Italy UN Doc CRPD/C/ITA/CO/1 (6 October 2016), para 56.

[73] Concluding observations Chile UN Doc CRPD/C/CHL/CO/1 (13 April 2016), para 49.

[74] ibid para 50.

[75] Committee on the Rights of Persons with Disabilities, General Comment No 4 on the right to inclusive education, CRPD/C/GC/4, 25 November 2016, para [9].

This means that conference organisers have a corresponding duty, which has to be regulated for by the state if conference organisers do not have appropriate processes to ensure respect for this right.

Naturally, the starting point for conferences on mental health and mental capacity issues is that it cannot be considered relatively unimportant to consider service user participation and engagement, given the impact on service users of the law in this area. To deny this starting point would be akin to holding the view that the identification and amendment of "all legislation which contained provisions that reflected the stereotypical assumption that a person was incapable of performing certain public or fiduciary roles because they were mentally disordered"[76] is a minor and technical matter. However, any and all areas of exclusion are problematic, and are often experienced cumulatively by persons with experience of disability so as to make social exclusion both prolific and pervasive. Hence we must be prepared to consider and address all aspects of our endeavours.

Naturally, no-one will suggest that resources be wasted by making arrangements that are not going to be needed, meaning that it is proper to require an advance indication of needs. At the same time, universal design ideas should be to the fore, since they will not diminish the conference experience for those that do not need those extra services. Applying this approach to conferences that will, or may well, involve the participation of service users, those who want to facilitate conferences that are 'good' from service user perspectives, and in accord with the obligations of the CRPD, must focus on the question: What needs to be done to enable the full and effective participation and inclusion of people with experience of disability? In accord with the social model of disability the answering of this question is about addressing the attitudinal and environmental barriers that hinder service users' full and effective participation in conferences on an equal basis with others.

To our mind, the starting points of inclusion and universal design lead to two essential components:

> Involving service users in all stages of the planning of the conference from the outset and through to the culmination of the evaluation.
>
> Valuing the knowledge and perspective that service users bring to any mental health related subject and event – service users must feel valued, respected, included and listened to.

Full and effective participation means consideration and facilitation of meaningful service user participation in all aspects of the conference – whether as key-note presenters, as concurrent session presenters, as poster presenters, as panel members, as active audience members, and as social and networking event attendees, supporting the enjoyment of freedom of thought and expression through all avenues and in all capacities.

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[76] Mental Health Foundation of New Zealand. (2008). *Submission to the Universal Periodic Review Relating to the Situation in New Zealand of People Living with Mental Illness.* Retrieved from http://www.mentalhealth.org.nz/file/Policy-Advocacy-etc/Documents/Submission-Universal-Periodic-Review-10-November-2008.doc.

In order to do this, attitudinal and environmental barriers must be considered and addressed. These can include travel, cost, feelings of being ‘other’ and/or a ‘token’, out of place, overwhelmed, isolated, and over-stimulated, and alcohol related events.

The principles of universal design that can address these barriers and support full and effective participation of service users at the group level include, but are not limited to, the availability of scholarships to support attendance, ‘live-streaming’ options for presenting, flexibility of presentation times, presentations on stand-by (to fill in if people become unwell), early provision of conference information, quiet rooms, regular breaks, water available at all times and in all venues, preferential seating, screening out of external (environmental) stimuli, conference ‘buddies’, asking service users if they would be prepared to be called upon to provide a service user perspective (prior to the start of any session), and ‘dry’ options at social events.

In addition, conference organisers should promote through conference communications that reasonable accommodations are available and involve a process for service users to advise and be supported with any particular needs.

Organising of conferences based on these suggestions and guidance would mean, at the very least, that the recent experience of one of the authors, and the significant harm that resulted from that, could be avoided. The fact is that with relatively little effort service users can be supported to fully and effectively participate in conferences and the benefits of that, to all involved, will be immense. That’s why these small steps are a good idea, beneficial to all. If you have colleagues and conference organisers that do not accept this, then you can fall back to the indication we have sought to demonstrate via the analysis of the CRPD: it’s also a requirement of international human rights law.

WHY FUTILE AND UNWANTED LIFE-PROLONGING TREATMENT CONTINUES FOR SOME PATIENTS IN PERMANENT VEGETATIVE STATES (AND WHAT TO DO ABOUT IT): CASE STUDY, CONTEXT AND POLICY RECOMMENDATIONS

JENNY KITZINGER AND CELIA KITZINGER*

ABSTRACT

In August 2017 a judge sanctioned withdrawal of clinically assisted nutrition and hydration from a patient who had been sustained in a vegetative state for twenty-three years, finding it "overwhelmingly in his best interests" for treatment to stop, allowing him to die. Injured in 1994, this patient had continued to receive life-sustaining treatment long after clinicians, and his family, had abandoned any hope for recovery and with no evidence that he would have wanted to be kept alive this way. Based on interviews with his parents, and the court hearing, we explore how it came about that he received this treatment for so long. We contextualize this in relation to our wider research about the treatment of severely brain injured patients and ask why, despite guidelines, policies and statute concerning best interests decision-making, thousands of patients in permanent vegetative states are similarly maintained in England and Wales without any formal review of whether continuing clinically assisted nutrition and hydration is in their best interests. We consider the implications for ethics, policy and practice in relation to patients with prolonged disorders of consciousness more broadly, highlighting in particular the actions that need to be taken by clinicians, inspection bodies, Clinical Commissioning Groups and Health Boards across England and Wales.

I. INTRODUCTION

The problem of futile treatment for patients in a permanent vegetative state (PVS) is often laid at the door of families who insist on life-sustaining treatments that clinicians deem inappropriate. This may arise from families' failure to accept the devastating nature of their relative's brain injuries or from a 'natural instinct' to cling to hope for recovery – or because, although they understand the clinical facts, they dispute the 'futile' label, believing that any life is better than none. Even if a family believes that the patient would not want to be kept alive and accepts certain ceilings of treatment (e.g. no resuscitation or no return to intensive care), they may resist cessation of other interventions - most notably clinically assisted nutrition and hydration (CANH – also known as 'artificial' nutrition and hydration, ANH). Such resistance is often underpinned by the powerful symbolic values associated with feeding, fear of a 'bad death' and doubt about – or rejection of - the ethical/legal distinction between treatment withdrawal and active euthanasia [see endnotes 1-3]

The solution is often presented as "effective communication" whereby "the medical team gives pertinent information, checks its reception, [and] takes appropriate action in order to diminish family anxiety" ([1] pp 919-920). This advice assumes, of course, that the medical team is proposing to withhold or withdraw treatment and that families are

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insisting that life-sustaining treatments are given. Such situations exist, of course, but our recent research [4] and experience in supporting family members of patients with catastrophic brain injuries [5, 6] highlights a different issue: that of medical teams who continue to deliver CANH (and other life-sustaining treatments) long after families come to believe that such treatments are unwarranted. We report on one such case here, concerning a patient who was maintained in a vegetative state for 23 years.

We contextualize this case study in relation to our broader work with 85 family members with experience of having a relative with a prolonged disorder of consciousness, and draw out implications for ethics, policy and practice. In particular, we argue that explaining the long-term futile treatment of PVS patients as due to intractable pressure from families, obscures the legal, institutional, clinical and organizational factors underpinning this state of affairs. Estimates suggest that up to 16,000 PVS patient [endnote 7] are being maintained in England and Wales today. We argue that an ethical response to this situation must go beyond a concern with family psychology and communication needs: it is imperative to address key structural issues.

II. MEDICO-LEGAL CONTEXT TO THE CASE

The patient, (we will call him G)[1] who is the focus of this article was injured in 1994. In 2017 the Court of Protection heard evidence that that he had been unconscious ever since his injury – and the judge ruled that CANH was "overwhelmingly" not in his best interests. These twenty-three years span over two decades of medico-legal development and media reporting in which the right not to be subject to futile or unwanted treatment has gained increasing attention across Europe, North America and beyond[2]. G was injured in the UK, the year after the landmark *Bland* judgment - which ruled that feeding tubes are medical treatment and can be withdrawn if not in the patient's best interests - indeed continuation of the treatment will, if not in the best interests of the patient, be unlawful[3].

At least five similar cases had been subject to court judgments by 1999[4], by which point G's diagnosis of PVS (originally made in 1995) had been confirmed on several occasions. The law required reconsideration of the *Bland* principles after October 2000 in light of the incorporation of the European Convention on Human Rights into domestic law (via the Human Rights Act 1998) – in particular Article 2 (right to life). Between 2000 and 2001 Butler-Sloss J heard at least another five additional cases concerning withdrawal of CANH from PVS patients in relation to 'right to life', and found in each case that

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[1] The patient's full name is in the public domain. However, as his parents would have preferred his name not to be published, we have chosen to refer to him only as 'G' in this article. This was the initial used in the court hearing (Case No. COP 95043878).

[2] Highly publicized cases include: Terri Schiavo (USA), Eluana Englaro (Italy); *Re a Ward of Court (withholding medical treatment) (No. 2)*, [1996] 2 I.R. 79; [1995] 2 I.L.R.M. 401; Aruna Shanbaug (India).

[3] *Airedale NHS Trust v Bland* [1993] A.C. 789; [1993] 2 W.L.R. 316

[4] *Frenchay Healthcare NHS Trust v S* [1994] 1 W.L.R. 601; [1994] 2 All E.R. 403. *Swindon and Marlborough NHS Trust v S* (unreported - but see; Guradian Dec 10 1994; Med. L. Rev. 1995, 3(1), 84-86); *Re D (Medical Treatment: Mentally Disabled Patient)* [1998] 2 F.L.R. 22; [1998] 2 F.C.R. 178; *Re H* (A Patient) [1998] 2 F.L.R. 36; [1998] 3 F.C.R. 174

withdrawal was lawful and in patients' best interests[5].

On the medical front, the House of Lords' Select Committee on Medical Ethics[6] had recommended, immediately post-*Bland,* that a code of practice should be developed. A working group convened by the Royal College of Physicians (RCP) undertook a review and published the Guidelines for the Diagnosis and Management of the Permanent Vegetative State in 1996, endorsed by the Conference of Medical Royal Colleges and their Faculties in the UK[7]. These guidelines were revised and updated in 2003 [endnote 8] and again in 2013 [endnote 9]: both iterations clearly highlight ongoing life-prolonging treatment for PVS patients as futile[8].

In 2007, the implementation of the Mental Capacity Act 2005 incorporated into statute the requirement that; "An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests" (s.1(5) MCA), and explicitly required a best interests assessment of all treatments delivered to incapacitated patients. Since then a whole raft of academic articles, training initiatives and resources have been produced to support professionals in implementing good practice and following the law relating to patients in PVS. Refinements and clarifications continue to be developed.[9]

The question we address here, then, is how did it come about that a patient who was correctly diagnosed as PVS on multiple occasions (and regularly assessed by professionals) continued to receive life-prolonging treatment for more than two decades, despite case law, professional guidelines, and statutes that should collectively have led professionals – ever since the 1990s - to the view that life-sustaining treatment was futile and not in his best interests? We will answer this question with specific reference to the particular circumstances of G's case, but the relevance of the answer goes far beyond it, insofar as it enables us to interrogate some of the structural and institutional forces that result in thousands of patients in PVS and other prolonged disorders of consciousness being maintained with life-sustaining treatment in England and Wales today, often without any consideration of the best interests of the individual.

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[5] *NHS Trust A v M*, *NHS Trust B v H* [2001] Fam 348; *NHS Trust v P* (unreported) see – digest [2000] All ER [D] 2363; *NHS Trust A v H* [2001] 2 F.L.R. 501; [2002] 1 F.C.R. 713; *Re G (adult who lacks capacity: withdrawal of treatment*) (2001) 65 B.M.L.R. 6.

[6] Report of the Select Committee on Medical Ethics (1993-4, HL Paper 21-I)

[7] see – Information from judgment of Sir Stephen Brown P in *Re D (Adult Medical Treatment)* [1998] 1 F.L.R. 411; [1998] 1 F.C.R. 498

[8] RCP 2003 guidelines [8] say: "When the diagnosis of a permanent VS has been made ... further therapy is futile. It merely prolongs an insentient life for the patient, and a hopeless vigil entailing major emotional costs for relatives and carers" (para. 3.5). Under such circumstances, the diagnosis "should be discussed sensitively with relatives, who should then be given time to consider the implications, including the possibility of withdrawing artificial means of administering nutrition and hydration" (para 3.6).

[9] These include forthcoming revised guidelines from the British Medical Association (due in Summer 2018) concerning clinically assisted nutrition and hydration for these (and other) patients without capacity to consent to it who may be treated long-term. Consensus statements have also recently been produced regarding the treatment of patients with devastating brain injuries in the early days/weeks (long before a 'Permanent' diagnosis can be given) e.g. stating that 'where patient-centred outcomes are recognized to be unacceptable, regardless of the extent of neurological improvement, then early transition to palliative care is appropriate' [10, p138].

III. OUR INVOLVEMENT WITH THE G CASE: SUPPORT, RESEARCH, ANALYSIS

The case history we present here is based on a three and a half hour in-depth narrative interview with G's parents (interviewed as a couple). Our understanding of what they told us is also informed by our personal involvement with the family – witnessing at first hand some of what they went through. They initially approached us for help in Spring 2017 as a consequence of our research and outreach in this area (see www.cdoc.org.uk for more details about this work). We subsequently supported G's parents in obtaining (yet another) expert diagnostic opinion and helped with the legal procedures. The first author (Jenny) accompanied the parents to three best interests meetings, and we both attended the court hearing. The second author (Celia) acted as litigation friend for the patient. We have had around 30 hours of face-to-face contact with G's parents[10] across a range of settings and have also spoken with his clinical and legal teams.

Alert to the difficulties of retrospective self-report data (especially covering such a long period), we have cross-checked the parents' recollections with other sources of information so as to further objectify the matter. A draft of this article was sent to various lawyers and clinicians involved in the case and we have incorporated relevant feedback and corrections. We also locate the parents' narrative in the context of our broader research with a range of families with PVS (and MCS) relatives in order to build up a multi-dimensional insight into the varied and complex factors that shapes patient pathways.

IV. RESEARCH ETHICS

The broader research programme of which this is a part has been approved by Ethics Committees at the Universities of York and Cardiff and received NHS approval from Berkshire Research Ethics Committee[11]. Explicit (written) consent has been obtained for all direct quotations not already in the public domain. The patient's parents were offered the opportunity to give feedback on our summary of their account and they support the publication of this article and the use of their words. The patient himself lacked capacity to give consent – but his parents believe he would have accepted the importance of writing about this case.

Our involvement with G's parents included offering support and information drawn from our experience as researchers and as family members with a sister with profound brain injuries. We have described elsewhere [endnotes 11, 12] some of the ethical challenges raised by our different roles and relationships (as both 'insiders' and 'outsiders' and as both participants and as researchers immersed in a complex medico-legal context). Although this much broader experience undoubtedly informs our understanding and approach to analysing what happened, we have not explicitly drawn on it in this article. In particular, we have not used any privileged information gained as part of our role in

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[10] The patient's wife withdrew from involvement with G in 1997 and divorced him soon afterwards. She has not seen G, or had any involvement in decisions about him, for the last twenty years and it was not considered appropriate to contact her.

[11] Research Ethics Committee reference number: 12/SC/0495

advocating for the patient or his family.

V. MEDICAL ASSESSMENTS AND INTERVENTIONS: A PATIENT 'LOST IN PLAIN SIGHT'

G was 24 years old when, in November 1994, he became trapped in a machine at work. His oxygen was cut off for around 15 minutes and, when he was released from the machine, he went into cardiac arrest. He was left with severe hypoxic brain damage. He was resuscitated and rushed to hospital. Subsequent treatment included assisted ventilation and a series of surgical interventions over the first six months including tracheostomy and PEG insertion, the latter allowing G to be fed via a tube directly into his stomach. He was assessed for one year at a specialist rehabilitation centre leading to a formal diagnosis of PVS in November 1995, a year after his original injury, a diagnosis which was confirmed (after a second placement in another specialist rehabilitation centre) by expert reports in 1997, 1998 and 1999.

An insurance settlement, along with Continuing Health Care funding and extensive family input, ensured that G received excellent 24-hour care at home after his initial period in hospital and rehabilitation. Ongoing medical interventions included the provision of CANH and frequent PEG replacements, inoculations against influenza, and antibiotics for potentially life-threatening infections. He was regularly seen by a wide range of medical professionals as well as having annual assessments at a specialist brain injury rehabilitation unit and/or home visits and also reviews by the Health Board responsible for his Continuing Health Care funding.

This is not a case where the diagnosis was unclear, nor was the patient 'warehoused' without appropriate access to rehabilitation and assessment (as can happen in some cases [endnote 13].) However, in spite of all this attention, it seems that it was only after the parents raised the issue in 2016 that any professionals formally addressed the question of why ongoing life prolonging treatment was being provided to this permanently unconscious individual. This patient was, it seems, 'lost in plain sight'.

VI. THE PARENTS' EXPERIENCE: FROM HOPING FOR RECOVERY TO INITIATING DISCUSSION OF TREATMENT WITHDRAWAL

We summarise the parents' account of their experience in relation to: (a) the initial hospital admission; (b) the next two-and-a-half years before they began caring for their son at home; (c) two decades of home care; (d) the final 18 months after they raised the question of CANH withdrawal.

A. The Early Weeks (November/December 1994)

The parents talk about their son's initial period in intensive care and high dependency as a time of shock, hope and uncertainty: "*We lived in the hospital… praying please God, please, please God, let him breathe, let him be okay'*". As is typical of many families whose relatives survive only to be left in long term vegetative or minimally conscious states [endnotes 14, 15], G's parents now realise that they did not have any understanding of the possible outcomes e.g, that their son could breathe but still not be "okay".

As far as we can tell from the parents' memories of what happened, no reasonable efforts were made to communicate with them about G's prognosis or what his future might hold - although obviously their experience may not reflect what clinicians intended or thought they were doing at the time. The parents recall just one occasion where they overheard some discussion about whether life-prolonging interventions should be pursued: a surgeon asked G's wife what she would want to happen if anything went wrong in theatre. She replied "*Of course I want to save him, he's only twenty-four... That was said in front of us, <u>that</u> we witnessed*," says G's father, "*but there was nothing else"*. They subsequently encountered that same surgeon outside the hospital lift. G's father thanked him for doing the surgery, "*but he tore a strip off me and basically said that we'd be sorry".* In retrospect they believe there must have been further conversations between this doctor and their son's wife, and that the doctor wrongly assumed that the whole family was resisting his advice not to pursue life-prolonging interventions. However, they do not recall ever having been invited to contribute to any such discussion and did not feel that the surgeon's interaction with them outside the lift had offered an opportunity to explore options.

B. The First Two and a Half Years (Late 1994 to Mid-1997)

Just before Christmas 1994 their son was moved from the hospital to a specialist rehabilitation centre where he stayed for over a year. Again, his parents cannot recall any formal discussions about the value (or not) of life-prolonging interventions. There is just one passing remark that sticks in their minds: a nurse said, *"you've had a bereavement, you should be having counselling". G's* mother was shocked by the clear message that *"we'd lost him, the G we knew,"* but says that none of the medical staff actually sat down and talked them through their son's prognosis or the decisions that needed to be made. If, in fact, efforts *were* made to communicate with G's parents about these issues such efforts were clearly not successful.

After more than a year in the rehabilitation centre, G was discharged to the care of his wife. His parents were "*petrified"* and could not accept the implication that "*there was nothing more they [the doctors] could do".* They still hoped for recovery:

> *"I remember the doctor saying that when he comes home there'll be stimulation, cooking smells, the vacuum cleaner going, that this could stimulate G perhaps to becoming aware."* (Mother)

They were also encouraged by the 'stimulation kit' they were provided with – including blocks of wood (to bang either side of G's head), sandpaper to rub on his skin, and bottles of smells to stimulate his senses.

C. Two Decades of Caring at Home (1997-2017)

In 1997 their son was provided with a temporary placement in a second specialist centre for yet more assessment. It was after this that G's wife decided to stop looking after him at home and his parents took over. They were given copies of reports clearly stating that G was in a permanent vegetative state - PVS, but say they tried to ignore this: "*P, V, S – three letters we never wanted to utter ourselves to anybody*".

In any case, documents produced as part of compensation settlements commonly incorporate unquestioned assumptions about continuation of life-prolonging treatment: there is often no consideration of treatment-withdrawal, nor any suggestion that the treatments provided might be time-limited. Instead, they presume that life will be sustained and are oriented towards the nature and cost of the care package. G's parents were left clinging to hope ("*like the miracles you read about in the newspaper*") and tried to imagine that their son had some level of consciousness. They encouraged his care team to do the same:

> "*He looks as if he's conscious, doesn't he? ... [We'd say] 'oh look, he's looking at you'. And we also encouraged that with [the carers], in order to have the best care for C, you know, so that he was really being looked after, be it just his body."* (Mother)

Gradually, however, "*we realised we weren't seeing any change ... there was just this for him. This was his life – no life at all really".* They came to believe that "*no-one would want this*" and reflected on the contrast between his current existence and everything their son had once valued - his love of socializing, commitment to community charities and the fact that he had put thought into what he wanted after he had "gone" e.g, he carried an organ donor card and had taken out life insurance to protect his wife's financial future. Although now certain that he would not have wanted to be kept alive in his current state, "*we didn't know there was any option"* (Father); "*no one has ever said, 'Look, there is another path for [him], he doesn't have to stay like this*" (Mother).

After some years (they estimate around 10 years after their son's initial injury), the parents nervously initiated a discussion of ceilings of treatment by asking for 'no return to hospital' and 'Do Not Attempt Cardio-Pulmonary Resuscitation' to be put on G's records. This was done but it seems that none of the clinicians looking after G responded by inviting a review of <u>other</u> life-prolonging interventions – in particular ongoing clinically assisted nutrition and hydration.

D. The Final 18 Months

It was in January 2016 that G's parents confronted the possibility of withdrawing his feeding tube as an option. Such consideration was prompted not by information or support from *clinicians* but by reading a magazine article about another family's experience of this being done for a PVS family member. The parents raised the possibility of CANH-withdrawal with their son's GP who, although initially appearing "startled", offered his full support. The GP moved quickly to refer G to a palliative care specialist who visited within a few days, reviewed G and put ceilings of treatment in place in respect of antibiotics. Some of the front-line staff who had been caring for G over many years apparently supported this move and were relieved to see such decisions enacted, but others resisted it – and were very distressed.

From this point the case moved slowly towards court, though it was 18 months after this conversation with the GP before it actually went before a judge[12]. Although a

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[12] We have written elsewhere about the delays typically introduced at this stage [endnotes 4, 5]. In this case the first up-to-date independent assessment was not provided until January 2017; it is unclear

solicitor was instructed by the Health Board in early 2016, the application was not lodged until summer 2017. Most of this delay was caused by the process of getting the evidence for the application together – including getting two more, up-to-date, expert assessments. The second report was considered advisable after two carers – opposed to stopping treatment - raised the possibility that G had some awareness, citing examples such as a startle response to loud noises and moving eyes in ways which, they believed, were deliberate actions in response to sounds. It is quite common for carers to raise such concerns at the point at which treatment-withdrawal becomes an issue. The second expert assessment in 2017 confirmed once again - for the sixth time since his injury – that G was in a PVS; systematic testing of some of the behaviours reported by carers found these to be reflexive or spontaneous,i.e random, rather than prompted by external stimuli, and the consultant concluded that there was no evidence of any conscious awareness.

When G's parents initially approached us for support (in 2017, between the first and second additional independent diagnostic assessments), they felt that life-prolonging treatment had continued for far too long and were frustrated and distressed by the time it was taking to get the case to court. They looked back over what had happened in the preceding two decades and expressed great concern:

> *"All we're doing is looking after G's body. We've just accepted it over the years. But now I feel we've not done enough. We've just cared for him, not thought about what we should do for him."* (Mother)

G's father added: *"I worry that we have been negligent",* but he also drew attention to the responsibility of clinicians to raise CANH-withdrawal.

> *"We were going over for a yearly checkup at [the specialist centre]. They'd check 'What's his medicine?', 'What's his weight?'. And we'd try with the awareness kit: sandpaper, oils, wool. And the doctor said 'keep on doing that if it keeps you happy but don't beat yourself up'. He obviously knew – but still nothing was said. They probably thought we were in denial and we probably were. But doctors have these seminars – they have research papers come through – shouldn't they have known? Shouldn't they have said something? Why didn't anyone say anything?"* (Father)

VII. DISCUSSION AND RECOMMENDATIONS

It seems that there were significant failures to follow relevant case law, guidelines and statute in this case. These apparent failings date back initially to the 1990s: there was no formal consultation with the parents when clinicians made decisions about life-prolonging treatment while their son was in hospital or when he was subsequently transferred to specialist assessment settings. Even once the PVS diagnosis was confirmed for the fourth time (in 1999) and G's parents took on the responsibility of caring for him at home, clinicians apparently still failed to initiate such discussions with

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why this took so long given that the parents had raised the issue a year earlier. The second assessment came six months later, delayed, in part, by the fact that the most relevant specialist service had a long waiting list (especially for patients with tracheostomies). This was eventually resolved by transferring G to yet another specialist centre (the third specialist unit to take him – and one outside the usual area) – a positive example of flexible responses to circumvent the possibility of drawing out the whole process still further.

them – and those responsible for determining their son's best interests (which includes a range of health care commissioners/providers/inspectors) – seem not to have made any such determinations.

A. Organisational Communication, Missed Opportunities and Treatment-By-Default

One issue is apparent, failures in communication between the different professionals and organisations involved in the 1990s (such that the repeated diagnoses of G as being in a PVS) may not have been communicated to the commissioning/funding body: if this is so then there cannot have been appropriate consideration of G's best interests, including (but not limited to) the question of whether continuing CANH was in his best interests. It seems no one joined the dots between the multiple confirmed PVS diagnoses and best interests decision-making.

From the parents' reports it is also evident that opportunities to question the assumption that treatments would be provided indefinitely were missed at routine clinical interventions and at regular reviews over the years that followed. These opportunities included frequent PEG replacement by a specialist who regularly came to their home, the annual reviews when G was taken to the specialist rehabilitation centre (assessments which went on for many years), and also the annual reviews carried out by the Health Board assessing his care needs. Another opportunity for professionals to comply with guidelines and statute was missed when G's parents initiated discussions about whether some life-prolonging interventions (e.g, CPR, returns to hospital) could be withheld/withdrawn. At that point, nobody seems to have used the opportunity to raise the issue of other life-prolonging interventions – in particular CANH.

Overall, what we see in this case is that instead of treatments being decided by reference to G's best interests, an entire infrastructure and reams of official documentation supported treatment-by-default. This was implemented in the complete absence of any evidence that it was in his best interests, and in the face of ample evidence that it was futile and possibly unlawful – and long after his parents had come to believe he would not have wanted his life prolonged.

G's story is exceptional for the length of time he was sustained in PVS - and also for the fact that court proceedings were finally initiated which allowed his death. But the failings in G's case echo what we have found in our wider research [endnotes 3-6]. Families, and staff too, feel trapped in a system of 'care delivery' which seems to have its own logic and momentum. It seems that some of the health care workers involved in G's care had been deeply troubled by the situation but did not know there were options, or did not feel they had the skills to challenge what was happening, or felt it was not their place to raise the question of whether or not continued life-prolonging treatment was right. Others may have simply found the option of CANH-withdrawal ethically unacceptable. Even once the parents initiated the discussion and the Health Board started proceedings there was still an additional delay before the case reached court. As a result of all these factors G's human right not to receive futile and unwanted treatment was breached for decades.

B. Lessons Around Support/Training Needs

There are important lessons to be learned from G's case (and other cases of prolonged disorders of consciousness more generally across the UK) including the following:

a. It is essential that family and staff understand the medico-legal context and have access to high-quality information about clinical, social and ethical issues concerning treatment of this patient group

b. Families must be given appropriate information and support – including support over time and across different settings (including when caring for a patient at home)

c. Staff working in this area may need special training and support to address their own concerns and to develop the skills to have difficult conversations.

d. It is also important that staff have training and understand the responsibilities of their role (which includes acting in the best interests of patients as laid out in the Mental Capacity Act 2005, its associated Code of Practice, and in professional guidelines).

But repeated calls for such lessons to be learned - and the production of materials to support best interests decision making[13] - seem to have produced only very slow change. We think it is time to address key structural problems including the legal context and how care is inspected, commissioned and delivered.

C. The Legal Context

One such structural problem - the long-standing apparent requirement for judicial review of these treatment decisions in England and Wales - is already being addressed. We have discussed elsewhere the ways in which the belief – buttressed by Court of Protection Practice Direction 9E - that court applications are mandatory before CANH can be withdrawn from patients in permanent vegetative and minimally conscious states has acted as a deterrent to withdrawal [endnotes 4, 5]. Our analysis has highlighted how this can mean that many patients have continued to receive treatment that is not in their best interests either as they await court hearings, or because their case is not brought before the court at all. In an important recent development (which came, on 1 December 2017, just too late for G) the Court of Protection Rules Committee withdrew Practice Direction 9E.

This move away from the apparent need for court approval has also been clear in recent legal judgments.[14] A series of judges have made statements that there is no requirement

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[13] For examples of such resources see http://cdoc.org.uk/publications/resources-for-families-and-practitioners/

[14] *NHS Trust v Mr Y (By his Litigation Friend, the Official Solicitor) and Mrs Y* [20017] EWHC 2866 (QB) (available at www.bailii.org/ew/cases/EWHC/QB/2017/2866.html); *Director of Legal Aid Casework & Ors v Briggs* [2017] EWCA Civ 1169; [2018] 2 W.L.R 152 (available at: www.bailii.org/ew/cases/EWCA/Civ/2017/1169.html); and *M v A Hospital* [2017] EWCOP 19; [2018] 1 W.L.R 465. (available at:

on treating clinicians to seek the court's prior approval to withdraw CANH for a patient in PVS or MCS where existing professional clinical guidance has been followed and where the treating team and those close to the patient are all in agreement that it is not in the patient's best interests to continue such treatment. A joint statement by the British Medical Association, the Royal College of Physicians and the General Medical Council underlines this point [endnote 19] and the Supreme Court hearing on this matter (Re. Y, UKSC 2017/0202) in February 2018 should remove any final doubt about the circumstances under which court applications must be made before CANH can be withdrawn.

D Ensuring that Best Interests Considerations are Integrated Into the way Care is Inspected, Commissioned and Delivered

Although removal of the perceived need to go to court will be an important step towards getting rid of one source of delay, it is clear that this will not completely resolve the problem of treatment-by-default for patients in permanent vegetative states – or indeed in other prolonged disorders of consciousness e.g, vegetative states that are not yet diagnosed as 'permanent' or minimally conscious states. Our analysis of the G case (and other cases we have examined) shows that additional changes are required to ensure that all decisions about these patients are the outcome of robust best interests procedures.

We recommend that organisations responsible for *inspecting* care (e.g. the Care Quality Commission in England and the Healthcare Inspectorate in Wales) should hold those responsible for providing care accountable for high quality best interests decision-making. This could include routinely asking for evidence of best interests decision-making for CANH for patient in a prolonged disorder of consciousness.

We also recommend that those responsible for *funding and commissioning* care (Clinical Commissioning Groups in England; Health Boards in Wales) should take responsibility for ensuring that all treatment they commission is in the best interests of the patient – and require this to be clearly supported by the correct documented evidence. Alongside this, it is essential that they provide the appropriate resources to allow this to happen, including access to independent expert second opinions as required, and it is vital to ensure that CCGs and Health Boards know where patients are – and that information is exchanged and their treatment is appropriately co-ordinated.

Despite some reorganization of the health service and despite new guidelines and procedures, it is clear that what happened to G is probably still happening to other PVS patients today. Although Health Boards and Clinical Commissioning Groups provide the funding for treatment of PVS/MCS patients, it seems they do not know how many PVS (or MCS) patients are being maintained on their books. Clinicians regularly tell us that this is the case and this is supported by the results of a Freedom of Information request: only 62 of the 238 health authorities approached by the BBC could provide any

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www.bailii.org/ew/cases/EWCOP/2017/19.html).

information on how many such patients were their responsibility [endnote 16]. In addition, Health Boards and CCGs do not have any process of monitoring or assessing this ongoing treatment.

Change is urgently needed to ensure the appropriate care for patients like G. On the basis of our analysis of this case (and others), we support recent recommendations [endnote 17] for implementation of a clinical pathway based on the principles embodied in the Mental Capacity Act 2005 combined with the use of time-limited treatment-trials. This includes the following recommendations:

> Service commissioners should create and fund a centralized register, and require all services to put people entering (or already in) a prolonged disorder of consciousness on this register.
>
> Patients must have access to *the appropriate level* of diagnostic and prognostic expert assessment. By ‘appropriate’ level of diagnosis/prognosis we mean to the level of precision or (un)certainty that *the patient* would have wanted to ensure their wishes can be respected in best interests decisions about them. This does not necessarily mean fine-tuning the prognosis indefinitely but does mean access to the best high-quality information available at the time.
>
> Patients must have access to *timely* assessment and reassessment. By ‘timely’ we mean as specified in the latest guidelines (e.g. RCP (2013) at time of writing, and the new BMA guidelines due out in Spring/Summer 2018.
>
> Each patient (and their family) should have an assigned care coordinator, providing continuity and following the patient over time and across diverse services: this person’s role could include high-level understanding of the issues for VS/MCS patients, responsibility for ensuring that accurate information is available to the right people and appropriately entered into decision-making processes, and support for the family in navigating the systems responsible for the care of their relative. [See 18]
>
> There needs to be a clear line of responsibility for decision-making. Although – according to s. 5 of the Mental Capacity Act – everyone who “does an act in connection with the care or treatment of another person [who lacks capacity to consent]” is responsible for ensuring such treatment is in the patient’s best interests. This does not seem to be happening in practice. Currently there seems to be some doubt about who is responsible for the decision to continue administration of CANH for patients in prolonged disorders of consciousness and the responsibility for the act of giving the treatment is, in practice, diffused between different persons/bodies, none of whom may 'own' the decision. The responsible clinician for patients cared for at home (like G) or in long-term care homes is often considered to be the GP, who may see the patient infrequently and only when they become ill (e.g. with a lung infection): the GP may not feel they have the relevant specialist expertise or authority to question ongoing CANH and even the clinician replacing a PEG may not take responsibility for a best interests assessment (although they, of course, should). The funding/commissioning organisation is clearly identified as carrying key responsibility in the RCP guidelines [9] but often sees themselves as dependent on medical advice as to what treatments should be funded and do not in practice seem to necessarily apply best interests considerations to that advice. Often both health care staff and organisations abdicate responsibility, quite wrongly, waiting for ‘the family’ to raise questions about withdrawal.

A key underlying necessary condition here is initiating and following best interests decision-making procedures for all patients in prolonged disorders of consciousness. We recommend that commissioners should require services to hold regular best interests meetings that are properly, skillfully and sensitively conducted, and documented to comply with the Mental Capacity Act. This includes:

> Regular best interests meetings should be backed up by appropriate information for, and support for families (and staff as necessary) - including access to independent second opinions as appropriate.
>
> Staff should not rely on consulting just one person acting as 'next of kin'. Instead, as specified by the MCA Code of Practice, the decision-maker has a duty to consult (1) anyone named before loss of capacity (2) anyone caring for the person (3) close relatives and friends and (4) any legally appointed attorney or deputy (MCA Code of Practice, para 5.49).
>
> Meetings should explicitly address what the patient would have wanted (not just asking family members what *they* want, or asking them to make the decision)
>
> Such best interests meetings should explicitly address whether or not each and every treatment is in the patient's best interests – including asking that question about CANH
>
> It should be made clear that discussing treatment-withdrawal options is not about 'abandoning' the patient or withdrawing 'care': it is about ensuring appropriate, person-centred care. The discussion should include information about palliative pathways and accurate information about other families' experiences [20].
>
> Best Interests decision processes and outcomes should be properly documented

We agree with Professor Derick Wade that if commissioners: "funded a register and only paid providers if appropriate standards derived from national guidelines were met, then the situation could be transformed" [endnote 14].

VII. CONCLUSION

In conclusion, patients in prolonged disorders of consciousness (whether in a prolonged coma, vegetative or minimally conscious state) are extremely vulnerable and there are many challenges confronting their families who are faced with excruciating loss, accompanied by early prognostic uncertainties and conditions which are very difficult to understand. Families have to negotiate complex issues relating to their own wishes, their relative's prior (and possible/imagined current) wishes and the likely persistence of hope for recovery fuelled by media (mis)representations and hype around scientific 'breakthroughs' and nurtured by the well-intentioned impulses of friends and acquaintances, and some health care staff whose motivation is to offer comfort. The healthcare service needs to provide a high level of care, support and governance to ensure that patients' best interests are served and to address the serious problem of futile/unwanted treatment delivered in England and Wales to some of this patient group. It should not be left to families – like G's parents here, or the wife of minimally conscious Paul Briggs [6] - to raise the question of, or advocate for, treatment withdrawal.

Dealing with this problem needs to move beyond scapegoating families as the source of the problem – or a focus on simply providing information and support to them (although this is a crucial part of the jigsaw) - and towards a recognition that the institutionalized provision of long-term treatment-by-default normalizes sustaining life in PVS making it difficult for families (or staff) to consider alternatives [21].

What happened to G, and to his family, is a stark illustration of what can go wrong for years, or even decades, when the system fails a patient. As his parents comment, if lessons can be learned from his case, that is one of the few things that can mean that the suffering and the futility of it all is more than "just a waste". We hope that the analysis presented here, and suggestions for policy/practice change can be part of G's legacy.

Postscript:

Organisations involved in G's case have responded proactively to the concerns raised in this article. An independent review of his notes has been commissioned and there are plans to create a working group to review current guidance and pathways for similar patients.

Acknowledgements:

We would like to thank G's parents for their willingness to share their experience and for their consent to use their words in this article. We would also like to thank some of the professionals involved for reviewing and commenting on our account of what happened and our analysis of the implications.

Conflict of Interests Statement:

We have family experience of catastrophic brain injury and prolonged disorder of consciousness. The second author acted as litigation friend for the patient in this case.

Note: Our research has been translated into a multi-media online resource about family experience of having a severely brain injured relative. You can see filmed interviews with other families like G's at www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/overview.

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REVIEW: MELBOURNE SOCIAL EQUITY INSTITUTE, UNFITNESS TO PLEAD AND INDEFINITE DETENTION OF PERSONS WITH COGNITIVE DISABILITIES; AND JUSTICE, MENTAL HEALTH AND FAIR TRIAL

KRIS GLEDHILL*

1. McSherry B, Baldry E, Arstein-Kerslake A, Gooding P, McCausland R and Arabena K, *Unfitness to Plead and Indefinite Detention of Persons with Cognitive Disabilities*, Melbourne: Melbourne Social Equity Institute, 2017;

2. Justice, *Mental Health and Fair Trial*, London: Justice, 2017.

Towards the end of 2017, the long-established legal reform NGO, Justice, produced its report, *Mental Health and Fair Trial*. The output of a Working Group chaired by retired appellate judge, Sir David Latham, it contains 52 recommendations for changes in the criminal justice process in England and Wales. These refer to all stages, from the investigation of crime through to the process of sentencing. At around the same time, researchers linked to the Melbourne Social Equity Institute at the University of Melbourne have published their report on *Unfitness to Plead and Indefinite Detention of Persons with Cognitive Disabilities*. The main focus of this report is the barriers faced by people experiencing cognitive disabilities and how appropriate supports are needed to allow access to justice on equal terms.

Two articles of the Convention on the Rights of Persons with Disabilities 2006[1] are of obvious relevance in this context. First, article 13 requires equal access to justice, with such “procedural and age-appropriate accommodations” as may be necessary to secure this. Secondly, article 14 provides the right to equal protection against arbitrary detention, and a component of this is that “the existence of a disability shall in no case justify a deprivation of liberty”.

The Committee on the Rights of Persons with Disabilities, the body of experts that exists by reason of article 34 of the Convention and has as its central task reviewing the implementation of the Convention, issued guidelines on article 14 in September 2015.[2] These make clear the view of the Committee that it is not permissible to detain someone on the basis of a risk posed to self or others that is linked to a psychosocial disorder or intellectual impairment.[3] Its rationale is that, in the first place, the drafters of the Convention expressly rejected language that would have permitted detention if there was an impairment plus an additional feature such as risk to self or others.[4] Secondly, the Committee notes that, in the context of liberty and security of the person being “one of the most precious rights to which everyone is entitled” (and specifically

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[1] (United Nations [UN]) 2515 UNTS 3, UN Doc A/RES/61/106, Annex, GAOR 61st Session Supp 49, 65. (Adopted) 13th Dec 2006, (Opened For Signature) 30th Mar 2007, [Entered Into Force] 3rd May 2008

[2] United Nations 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, Adopted during the Committee’s 14th session, held in September 2015, available from the home page of the Committee. http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx.

[3] Guidelines, paras 6, 10 and 13 relate to civil detention scenarios.

[4] Guidelines, para 7.

that persons with intellectual disabilities and psychosocial disabilities enjoy the right),[5] article 14 is "in essence, a non-discrimination provision", such that it:

> relates directly to the purpose of the Convention, which is to ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect of their inherent dignity.[6]

As such, detention in institutions "either without the free and informed consent" of the detainee or on the basis of a substitute decision-maker giving consent is arbitrary detention.[7] The position of the Committee is that if a person poses a risk to others, they should be dealt with by the criminal law or other laws (in short, the same response irrespective of whether there is an impairment or not);[8] and that if a person fails to secure psychiatric treatment they probably require, that should be viewed as no more than the consequence of the fact that the right to make choices "includes the freedom to take risks and make mistakes",[9] which has to be enjoyed equally by people experiencing disability.

Criminal processes that involve differential treatment – such as fitness to stand trial provisions – are criticised because they involve a "separate track of law" which invariably entails lower "due process and fair trial" rights, such that that they breach article 13 as well as – if detention is involved - article 14.[10] The Committee supports instead relevant support and procedural accommodations to ensure a fair trial following due process.[11]

Naturally, the existence in so many countries of unfitness to stand trial laws (not to mention civil commitment laws) means that, if the Committee is correct, a lot has to be changed. The Latham Committee, however, is sceptical of the need for the removal of unfitness to stand trial laws. At paras 1.14-1.19 of its Report, it expressly rejects the

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[5] Guidelines, para 3.

[6] Guidelines, para 4. This is reinforced by the non-discrimination and equal protection of the law provisions of article 5 (see Guidelines, para 5) and the recognition of the equal right to make autonomous choices in article 12 (see Guidelines, para 8).

[7] Guidelines, paras 8 and 10. It also breaches article 12; and the invariable corollary of treatment without consent also breaches articles 12 and 25 (the latter relating to healthcare matters) and may well be torture or inhuman or degrading and so in breach of article 15. See Guidelines, paras 10-12 for these points.

[8] Guidelines, para 14.

[9] Guidelines, para 15. This is noted to be part of article 12 as well.

[10] Guidelines, para 14. See also para 16, in which the Committee makes clear that it finds problematic declarations as to unfitness to stand trial or of incapacity to be found criminally responsible. Note also para 20, in which it suggests that there should be no use of "security measures" after findings of no responsibility in the ground of insanity. The Committee does not find problematic the idea of diversion from the criminal justice system per se, or the use of such approaches as restorative justice; but it does find it problematic for this to lead to detention under mental health laws and any treatment without consent: see para 21.

[11] Guidelines, para 14, endorsing the "United Nations Basic Principles and Guidelines on Remedies and Procedures on the Right of Anyone Deprived of their Liberty to Bring Proceedings before a Court", adopted by the Working Group on Arbitrary Detention, [UN Doc A/HRC/30/36] of 29th April 2015, at para 126. This refers to such matters as supported decision-making, the need for accessible buildings and information, deinstitutionalisation and independent living, and remedies for any breaches of rights. These are all consistent with the requirements of articles 9 and 19 of the CRPD (relating to accessibility and community living).

idea, commenting that it could not be consistent with human rights principles to allow a trial of someone lacking any insight into the allegation against them or ability to instruct their legal team.[12] Unfortunately, the Latham Committee does not engage with the CRPD Committee's Guidelines document summarised above: instead, they deal with the CRPD Committee's General Comment No 1 on the implications of article 12 of the CPRD and the need for supported decision-making.[13] However, there is also reference made to documentation prepared for a meeting under the auspices of the High Commissioner for Human Rights in September 2015, which noted that it was identified that fitness to stand trial procedures should be abolished;[14] accordingly, the Latham Committee's view as to the impropriety of the CRPD Committee's views would probably be the same.

The report from the Melbourne Social Equity Institute, at pages 22-26, gives a brief summary of the main principles arising under the CRPD. It suggests, at page 25, that there is ongoing room for debate as to whether they are impermissible or not. The project giving rise to the report also produced several academic articles relating to fitness to plead.[15] The conclusion of one of these was that the views of the CRPD "set a challenge ... to abandon current unfitness to plead law", and that although such wholesale change was "likely to be the one path that will lead to full respect for the rights" of those affected, incremental change in various areas was the more realistic path.[16]

This explains why the second part of the report is headed "The Disability Justice Support

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[12] They point out that the Law Commission of England and Wales also reached the conclusion that it was necessary to reform rather than abolish the unfitness to stand trial process: Law Commission, Unfitness to Plead (Law Com No 364, 2016).

[13] United Nations Committee on the Rights of Persons with Disabilities: General Comment No 1 (2014), Article 12: Equal recognition before the law [UN Doc CRPD/C/GC/1] (19th May 2014).

[14] JUSTICE, *Mental Health and Fair Trial*, London: Justice, 2017, p 17, text around fn 31, which refers to OHCHR, 'Expert meeting on deprivation of liberty of persons with disabilities: Background note' (9 September 2015).

[15] Arstein-Kerslake, Anna, Piers Gooding, Louis Andrews, Bernadette McSherry, *'Human Rights and Unfitness to Plead: The Demands of the Convention on the Rights of Persons with Disabilities' (2017) 17 Human Rights Law Review 399* is cited for the proposition that there is ongoing debate. Another article that focuses on Australia is Gooding, Piers, Anna Arstein-Kerslake, Louis Andrews and Bernadette McSherry, 'Unfitness to Stand Trial and the Indefinite Detention of People with Cognitive Disabilities in Australia: Human Rights Challenges and Proposals for Change' (2017) 40(3) *Melbourne University Law Review* 816. See also Piers Gooding, Anna Arstein-Kerslake, Sarah Mercer and Bernadette McSherry, 'Supporting Accused Persons with Cognitive Disabilities to Participate in Criminal Proceedings in Australia: Avoiding the Pitfalls of Unfitness to Stand Trial Laws', (2017) 35(2) *Law in Context* 64. For a review of various recent proposals for reforming unfitness to stand trial laws, see Gooding, Piers and O'Mahony, Charles 'Laws on unfitness to stand trial and the UN Convention on the Rights of Persons with Disabilities: Comparing reform in England, Wales, Northern Ireland and Australia', (2016) 44 *International Journal of Law, Crime and Justice* 122.

[16] Arstein-Kerslake, Anna, Piers Gooding, Louis Andrews, Bernadette McSherry, *'Human Rights and Unfitness to Plead: The Demands of the Convention on the Rights of Persons with Disabilities'* (2017) 17 *Human Rights Law Review* 399, 418. The report also indicates that universal accessibility rather than creating "separate justice procedures" is "the most comprehensive way to comply with human rights law": McSherry B, Baldry E, Arstein-Kerslake A, Gooding P, McCausland R and Arabena K, *Unfitness to Plead and Indefinite Detention of Persons with Cognitive Disabilities*, Melbourne: Melbourne Social Equity Institute, 2017, 58.

Program", which reports on research into the value of support persons working with lawyers in fitness situations to reduce the occurrence of findings of unfitness and the potential consequences. As the case of *Noble v Australia*[17] indicates, these consequences can be the most problematic aspect of the process: this case involved a man found unfit to stand trial and held in prison conditions because no other facilities were found suitable. The relevant law, in Western Australia, made no provision for the trial to occur if the person became fit, which was particularly problematic because, when Mr Noble sought to argue that he had become fit to be tried, the prosecutors concluded that there was inadequate evidence to support a conviction.[18] Mr Noble was detained for over 10 years before being released subject to numerous conditions even though there was by then no prospect of any conviction – and equally no way for him to have recorded the acquittal that the prosecution now conceded he deserved.

This arose from an unsatisfactory and out of date unfitness law in which a disposal followed from the finding. Even the more modern approach of investigating whether elements of the offence are made out commonly pose problems for defendants because the focus on the physical elements of the offence in question rather than mens rea elements. This means that an acquittal based on a lack of that mens rea, or reliance on such features as self-defence in an assault scenario, are essentially unavailable because they turn on the defendant's perceptions, which will not be investigated if he or she does not give evidence. Hence, being supported to the extent that the defendant is fit to stand trial may bring him or her significant advantages.

The Melbourne Social Equity Institute report sets out the positive aspects of using trained support workers, particularly for defendants from indigenous communities, who are disproportionately affected. It also discusses some of the potential frictions caused by support persons not having legal knowledge and potentially being compellable witnesses on the current state of the law. One of the potential advantages described is of the ability to produce a suitable package that would satisfy the prosecution that the matter could be diverted from the criminal justice system, producing potentially significant cost savings.

The Latham Committee is also supportive of such mechanisms. The use of intermediaries to facilitate communication is an established feature of the English criminal courts, though the Committee calls attention to it being a very limited number.[19] They also raise their concern that Practice Directions and appellate decisions undermine the prospects of intermediaries being available for the whole trial, apparently for cost reasons, reliance being placed instead on untrained judges and advocates to muddle through.[20] They suggest that the whole system should be revised

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[17] United Nations Committee on the Rights of Persons with Disabilities, Views Adopted by the Committee under Article 5 of the Optional Protocol, Concerning Communication No. 7/2012, [UN Doc CRPD/C/16/D/7/2012] (10 October 2016), [2017] MHLR 215.

[18] Indeed, it seems that the victims had recanted any allegations made: McSherry B, Baldry E, Arstein-Kerslake A, Gooding P, McCausland R and Arabena K, *Unfitness to Plead and Indefinite Detention of Persons with Cognitive Disabilities*, Melbourne: Melbourne Social Equity Institute, 2017, 17, and a newspaper report referred to at endnote 37.

[19] JUSTICE, *Mental Health and Fair Trial*, London: Justice, 2017, p 66, para 4.20.

[20] ibid p 67, paras 4.20-4.22.

and that the arrangements in place for witnesses who need intermediaries should be extended to cover defendants.[21] As for judges, the Latham Committee suggests that courts should have designated judges, with the relevant training, who take over the case management of all cases involving vulnerable defendants, with relevant protocols in place to ensure reasonable accommodations are made and supplemental powers such as the ability to require prosecutors to give reasoned decisions for proceeding.[22] Training for advocates is also supported, and the Committee notes that whilst there is a range of material already available for practitioners, the level of take-up is not known.[23]

A telling comment made by the Latham Committee, in understated language, is that, "It is something of an anomaly that so much reliance is placed on AAs during the investigative stage, yet there is no assistance provided to defendants at court". "AAs" are the Appropriate Adults who have to be secured for interviews with people suspected to be vulnerable. Failure to secure them means that there is a significant risk that any admissions in interview will be found inadmissible for failure to abide by the obligations to use an Appropriate Adult, required by the Police and Criminal Evidence Act 1984 and the Codes of Practice issued under it. The Committee, however, has various suggestions to make for steps at the investigation and charge stage: this includes having "liaison and diversion" professionals from health and social care services conduct screening of people in police custody in order to provide a more robust assessment of vulnerability at the outset; and properly trained prosecutors who can assess the need to charge, assisted by diversion panels of mental health practitioners who could coordinate a support package that might tilt the public interest away from prosecuting and into some form of diversion. As has been noted above, the Melbourne Social Equity Institute report makes the point that this will produce significant fiscal benefits.

The Latham Committee also makes recommendations as to changes at the sentencing stage, including the involvement of liaison and diversion professionals to make recommendations on options available to the court. Its views take on a sense of urgency when the context is set, which is the overrepresentation in the prison population of England and Wales of those who will be in need of mental health services of some sort: figures as to this are set out, though with the call for more research. Nonetheless, the Committee was able to say that:

> The greater prevalence of mental ill health and learning disabilities of those in contact with the criminal justice system points to a failing to appropriately address their concerns by the public sector at large. Ultimately it suggests that vulnerable people are being criminalised rather than given the support and treatment that they need.[24]

Similarly, the authors of the Melbourne Social Equity Report note that their specific concerns about fitness to stand trial laws should be viewed in the wider context, namely that "A growing body of research indicates that persons with cognitive disabilities are significantly over-represented throughout criminal justice systems of high-income

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[21] ibid pp 68-696, paras 4.24-4.25.
[22] ibid pp 70-73, paras 4.29-4.33.
[23] ibid p 60, para 4.8, and p 74, para 4.34.
[24] ibid p 13, para 1.6.

countries, including Australia" (and details relating to this are set out, supplemented by the intersectional problem for indigenous people).[25]

Both reports, which contain a wealth of references to other relevant research, make recommendations that ought to be taken seriously. They suggest and justify changes that should be considered across jurisdictions as efforts are made to improve the situation for defendants who are vulnerable but have the same right to access justice as anyone else. One can only hope that they do not get placed on the special shelf for worthy reports that are welcomed but never actioned. Fortunately, the Committee on the Rights of Persons with Disabilities will provide a constant reminder that things need to be made better, which can only increase the chance of action.

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[25] McSherry B, Baldry E, Arstein-Kerslake A, Gooding P, McCausland R and Arabena K, *Unfitness to Plead and Indefinite Detention of Persons with Cognitive Disabilities*, Melbourne: Melbourne Social Equity Institute, 2017, 13-14.