

Routledge Handbook of Mental Health Law

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First published 2024

ISBN: 978-1-032-12837-5 (hbk)

ISBN: 978-1-032-12840-5 (pbk)

ISBN: 978-1-003-22641-3 (ebk)

Chapter 21

The right to mental health care in mental health legislation

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DOI: 10.4324/9781003226413-27

The funder of the Open Access version of this chapter is The University of Dublin.

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THE RIGHT TO MENTAL HEALTH CARE IN MENTAL HEALTH LEGISLATION

Brendan D. Kelly

Introduction

On 7 May 1959, British scientist and novelist C. P. Snow delivered the Rede Lecture in Cambridge, which was subsequently published as *The Two Cultures and the Scientific Revolution* (Snow, 1959). Snow argued that the humanities and science had split into ‘two cultures’, with proponents of the humanities bemoaning scientists’ lack of familiarity with the humanities, but failing to recognise their own disengagement from science, and vice versa. The division between the ‘two cultures’ was, Snow argued, deeply detrimental to all who sought to solve the problems that humanity faced.

In this chapter, I argue that ‘two cultures’ have emerged with respect to rights to mental health and mental health care. On one side, organisations such as the United Nations (UN) and World Health Organization (WHO) issue declarations that fail to engage sufficiently with the social, medical, and scientific evidence base for mental health care or with the realities of service provision. On the other side, many mental health service-users and service-providers, seized by the urgency of providing health and social care to those in need, increasingly regard UN and WHO statements as too detached from reality to inform change, as evidenced by muted responses to the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006), despite the vast academic literature it continues to generate.

There are, in essence, ‘two cultures’ with respect to rights to mental health and mental health care. Nobody benefits from this situation and important opportunities are missed, most notably with respect to the CRPD.

In the middle, people with mental illness and their families often chart the most sensible course, finding positions to value on both sides, even though the balance between ideology and evidence in views adopted by international bodies is increasingly tilted in favour of ideology. I argue that each of the ‘two cultures’ needs to seek greater understanding of the other’s position in order to make rights to mental health and mental health care into useful realities, rather than futile battlegrounds of rhetoric.

The chapter starts with a brief background to human rights in this field, explores the draft views of the WHO and Office of the UN High Commissioner for Human Rights (OHCHR) on reforming mental health legislation, discusses the idea of a ‘right’ to involuntary mental

health care, and concludes with a call for greater understanding between the ‘two cultures’, more inter-disciplinary research, and enhanced collaboration in planning and delivering services in order to better protect rights in mental health care.

Background to the right to mental health

Key ideas underpinning human rights have lengthy histories in many political and religious traditions, with particular growth in interest during the eighteenth century (Freeman, 2002). In theory, increased articulation of civil and political rights throughout the eighteenth and nineteenth centuries should have, automatically and without discrimination, included the rights of people with mental illness. The historical experiences of the mentally ill, however, and especially their increased rates of institutionalisation, highlight the need for pro-active protection of human rights and dignity, especially among those who lack opportunity to assert these rights adequately for themselves. The need to provide dedicated safeguards for such rights was not to be formally recognised until well into the twentieth century (Kelly, 2016).

Against this background, and at a more general level, the Universal Declaration of Human Rights (UDHR) was adopted by the UN General Assembly at the Palais de Chaillot in Paris on 10 December 1948 (United Nations, 1948). The UDHR was presented as a non-binding statement of rights which recognises that ‘recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world’ (preamble).

The UDHR states that ‘all human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood’ (article 1). These rights are universal:

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

(article 2)

The UDHR makes reference to ‘health and well-being’:

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

(article 25(1))

The inclusion of economic and social rights in the UDHR was controversial and in 1966 two separate covenants were adapted by the UN General Assembly: the *International Covenant on Civil and Political Rights* (United Nations, 1966a) and the *International Covenant on Economic, Social and Cultural Rights* (United Nations, 1966b). The difference between the two covenants was that civil and political rights were to be implemented immediately, while social and cultural rights were to be implemented progressively. The *International Covenant on Economic, Social and Cultural Rights* recognises ‘the right of

everyone to the enjoyment of the highest attainable standard of physical and mental health' (article 12).

Detailed histories of the idea of a 'right to health' are provided elsewhere (Tobin, 2012; Wolff, 2012). For the purpose of the present chapter, key statements include the Constitution of the WHO, which says that 'health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity':

The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.

(World Health Organization, 2020; p. 1)

This statement places considerable responsibilities on governments to protect and promote good health (Gruskin et al., 2013), not least because the right includes both freedoms and entitlements, as outlined by the UN Committee on Economic, Social and Cultural Rights (CESCR) in 2000:

The right to health is not to be understood as a right to be *healthy*. The right to health contains both freedoms and entitlements. The freedoms include the right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation. By contrast, the entitlements include the right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health.

(United Nations Committee on Economic, Social and Cultural Rights, 2000; paragraph 8)

The CESCR adds that 'the right to health must be understood as a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health' (paragraph 9). Overall, the CESCR document makes the 'right to health' more practical, attainable, and actionable (Backman and Bueno de Mesquita, 2012). This is especially helpful when non-binding statements of rights can occasionally appear utopian or aspirational, rather than pragmatic or effectual.

In 2006, the CRPD articulated a right to health specifically in the context of 'persons with disabilities':

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

(United Nations, 2006; article 25)

Various other declarations about the right to health apply in specific regions around the world, including the Charter of Fundamental Rights of the European Union, which states:

Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A

high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.

(European Union, 2000; Article 35)

The strengths and limitations of such declarations are explored in detail elsewhere (McHale and Fox, 2007; Tobin, 2012; Wolff, 2012), along with increased application of the right to health in the area of mental health, especially over the past two decades (Department of Mental Health and Substance Dependence, 2004; Kelly, 2013). This growing literature supports not only the importance of this right in the field of mental health, but also the ethical argument for a right to mental health care, based on benefit to individuals and society (Green, 2000) and clear deficits in current service provision (Flaskerud, 2009). Fulfilling this right in practice is likely to be complex and to require an evolving combination of public activism, policy change, and law reform (Kelly et al., 2020).¹

Draft guidance on mental health legislation

Against this background, it is regrettable that a recent publication from the WHO and OHCHR presents significant cause for concern about the persistence of ‘two cultures’ in this area, demonstrated by a lack of engagement with systematic, clinical evidence, and a lack of critical, reflective thought. While forms of evidence other than scientific and medical findings are clearly essential for developing policy, no form of evidence should be de-emphasised when considering a topic as fundamental as the right to mental health care.

These issues are especially evident in the draft document about mental health, human rights, and legislation published for consultation by the WHO and OHCHR in June 2022, titled *Guidance on Mental Health, Human Rights, and Legislation*. The OHCHR sought input from ‘Member States, and relevant regional and international intergovernmental organizations; national human rights institutions, equality bodies, United Nations funds, programmes, and specialized agencies, organizations of persons with disabilities and other civil society organizations, experts, academia and any other interested party’ (World Health Organization/Office of the United Nations High Commissioner for Human Rights, 2022).²

It is important to emphasise that this was a draft document that was yet to be completed by the WHO and OHCHR and was, therefore, unlikely to represent the final position of either organisation. Even so, pre-consultation drafts often provide useful insights, and this particular draft presented many points of interest, including much that was valuable on topics such as ‘rethinking legislation’, ‘person-centered, recovery-oriented and rights-based mental health’, and ‘developing, implementing and evaluating legislation on mental health’. Throughout the document, however, the ‘two cultures’ issue was in clear evidence, starting with the opening paragraph:

Many people with mental health conditions and psychosocial disabilities, in particular, face wide-ranging human rights violations and discrimination, including in mental

1 See, for example: <https://sd27.senate.ca.gov/news/20220429-stern-bill-establish-right-mental-health-care-and-housing-heals-severely-mentally-ill> (Accessed 28 February 2023).

2 <https://www.ohchr.org/en/calls-for-input/calls-input/draft-guidance-mental-health-human-rights-legislation-who-ohchr> (Accessed 28 February 2023).

health care settings. Often, discriminatory practices are underpinned by legal frameworks, which fail to uphold human rights and to acknowledge the pernicious effects of institutionalisation, the over-emphasis on biomedical approaches and treatment options, and the use of involuntary psychiatric interventions.

(World Health Organization/Office of the United Nations High Commissioner for Human Rights, 2022; p. 8)

It is a matter of regret that the WHO and OHCHR did not present evidence to support this negative view and did not counter-balance it by articulating any of the benefits of current mental health legislation or psychiatric interventions. There is overwhelming evidence that psychiatric medications are just as effective as their counterparts in general medicine, and sometimes more so (Leucht et al., 2012). People with schizophrenia who take antipsychotic medication have half the risk of dying during 14 years of follow-up, compared to those who do not receive antipsychotics (Taipale et al., 2020). This includes significantly lower risks of death from cardiovascular disease as well as suicide. These findings remain significant and substantial even after controlling for age, gender, substance abuse, medical comorbidities, other medication use, and various other factors.

To put these results another way, cumulative mortality rates during 14 years of follow-up are 46% for people with schizophrenia who are not on antipsychotics, 26% for those on any antipsychotic, and 16% for those on clozapine (which is used for treatment-resistant schizophrenia). Treatments with similar benefits in cancer medicine or cardiology would be hailed as breakthroughs. That is not to say that antipsychotic medications help everyone equally (they do not), are without side-effects (they are not), or suffice on their own (they do not – they must form part of multi-disciplinary care). But accumulated scientific evidence shows clear, substantial benefits with antipsychotics in terms of both quality and quantity of life, so it is puzzling that this is not reflected in the WHO/OHCHR draft.

The scant weight attached to evidence in the draft was noted by others, including the National Secular Society:

While cultural sensitivity and holistic, person-centred and rights-based approaches are welcome inclusions into mental health care, we caution that use of the phrase ‘reductionist Western biomedical model’ may lead to policies which reject objective, scientific and evidence-based healthcare in lieu of ‘alternative medicine’ models that are not supported by evidence and may be based on religious views. Sometimes, ‘alternative medicine’ models are pushed by people with a specific religious or personal agenda who do not prioritise the healthcare needs of the patient ...The guidance should stress that, while cultural sensitivity is important, best practice mental health care should be objective and evidence-based.³

Hopefully, this will be addressed in more advanced versions, following consultation. The report, as originally drafted, returned repeatedly to what it termed the ‘biomedical model’:

³ https://www.ohchr.org/sites/default/files/documents/issues/health/draftguidance/submissions/2022-08-08/National_secular_society_response.docx (Accessed 28 February 2023).

The biomedical model, in which the predominant focus of care is on diagnosis, medication and symptom reduction, continues to be the most prevalent approach across existing mental health systems. As a result, social determinants that impact people's mental health are overlooked, resulting in persons with mental health conditions and psychosocial disabilities continuing to face higher rates of unemployment, poverty, homelessness, and incarceration.

(World Health Organization/Office of the United Nations High Commissioner for Human Rights, 2022; p. 16)

Rather than overlooking the social determinants of mental health, the papers referenced by the WHO and OHCHR highlighted these precise issues, as do many other publications throughout the psychiatric literature (see, for example, Kelly, 2005; Burns, 2013a; Burns, 2013b; Torrey, 2014; Kelly, 2022). These are social needs that psychiatrists and other mental health professionals have repeatedly highlighted over many decades, but which social care providers and policy-makers have repeatedly failed to meet. This is not the fault of what the WHO and OHCHR conveniently term the 'biomedical model'; these are social and political issues which mental health professionals highlight repeatedly, but lack the tools to solve.

Capacity, consent, and care

Other areas of the WHO/OHCHR draft guidance presented similar reasons for concern. The WHO and OHCHR wrote that:

It is important that the law clearly prohibits substitute decision-making in the provision of mental health care and support. This includes repealing the provisions that allow guardians and family members to make decisions for people receiving mental health care or support, as well as eliminating all instances in which the law allows the treating doctor to decide for the person in their 'best interests'. The law should also expressly prohibit health professionals from making decisions without the person's informed consent.

(World Health Organization/Office of the United Nations High Commissioner for Human Rights, 2022; p. 47)

There is general agreement that models of supported decision-making need to be developed, improved, and expanded, but there is minimal guidance about how to proceed when supported decision-making proves insufficient. On occasion, it is simply not possible, despite extensive efforts, to establish a person's 'will and preference' for periods of time. Regrettably, the draft WHO/OHCHR document chose to avoid dealing with such difficult cases in sufficient detail. Hopefully, this will be addressed in later drafts, but the avoidance of challenging topics was a repeated pattern in the pre-consultation draft and is common across other documents from the WHO and UN (e.g., United Nations Committee on the Rights of Persons with Disabilities, 2014).

The draft guidance went on to state that 'another common exception to informed consent, particularly used in mental health care, is the lack of "capacity" or "competency" to

provide consent. As noted, this exception is contrary to the CRPD' (p. 54). Notwithstanding the particular interpretation of the CRPD presented by the UN Committee on the Rights of Persons with Disabilities (United Nations Committee on the Rights of Persons with Disabilities, 2014), there is a widespread view among mental health service users and providers that the concept of 'capacity' is a valid one and is not 'contrary to the CRPD' (Dawson, 2015; Freeman et al., 2015; Gergel et al., 2021).

In England and Wales, the foreword to the *Independent Review of the Mental Health Act, 1983* noted that 'some will point out that we have not gone as far as to recommend fully implementing the [CRPD], or to be precise, how that is interpreted by the Committee charged with its implementation':

And they are right. We haven't. For example, the Committee's recommendations would include not just dropping the [Mental Health Act, 1983], it [would] also require us to end all forms of substituted decision making, which would have to include for example dropping the Mental Capacity Act as well. I agree that the Mental Capacity Act (MCA), or more specifically the Deprivation of Liberty Safeguards (DOLS), needs urgent reform, which is happening as we speak. But the idea that those who lack capacity to take decisions for themselves should have no protections, save supported decision making, against exploitation, excessive detention and so on, seems to me to be something that most people and Parliament will find difficult. I do not think that we are compelled to follow this interpretation, and we will not.

*(Independent Review of the Mental Health Act
1983, 2018; p. 12)*

The WHO and OHCHR, in their draft guidance, expressed the view that 'the CRPD Committee and other human rights mechanisms have asserted that all coercive practices in mental health services are prohibited under the CRPD' (p. 61). Following this, they recommended that 'legislation should clearly prohibit all involuntary measures', but noted that 'no country has yet eliminated all forms of coercion in mental health systems'.

As a result, the draft WHO/OHCHR document explicitly recommended that every country pursue a course of action that no country had found possible to date; i.e., completely eliminating coercion in psychiatric services. Rather than citing systematic evidence to support their suggestion, the draft WHO/OHCHR recommendation appeared to be based, in large part, on one particular interpretation of the CRPD – an interpretation that is poorly supported by the CRPD itself, is widely contested (see above), and conflicts fundamentally with the position of other UN bodies (see below).

The ultimate goal is undisputed: non-coercive care is always ideal, it should be pursued more rigorously, and all incidents of coercion should be regulated closely, recorded in detail, and reviewed with a view to future prevention. But while many countries have implemented coercion-reduction programmes,⁴ none have managed to eliminate it completely, as the WHO and OHCHR acknowledged.

Later in the draft document, the WHO and OHCHR articulated a very particular, unsourced account of highly coercive treatment of 'a person who is suicidal':

4 E.g., <http://hdl.handle.net/10147/627078> (Accessed 28 February 2023).

When a person is threatening immediate harm to themselves (e.g., threatening to cut themselves or jumping out of a building), traditionally, legislation will consider them at risk to themselves and therefore authorize the use of coercion. First responders, often police officers and firefighters, will intervene to contain the situation. This may include the use of physical or chemical restraints. The person will then be taken to an inpatient service where, in many cases, they will be involuntarily admitted and kept for many days, even weeks. On many occasions, due to risk considerations, the person will be placed in a seclusion room at the beginning of their stay.

(World Health Organization/Office of the United Nations High Commissioner for Human Rights, 2022; p. 63)

Again, the WHO and OHCHR did not provide evidence to support this account or indicate if they regarded this trajectory as typical or atypical.

While it is likely that the situation varies across countries, it is worth noting that in Ireland, for example, 82% of people who present to emergency departments with self-harm or suicidal ideation are not admitted to inpatient care, but are directed to community supports instead (Health Service Executive, Mental Health Division, 2017). Among all people admitted to inpatient psychiatric care in Ireland, 84% of admissions are voluntary rather than involuntary (Daly and Craig, 2021), and, among those admitted, fewer than 9% experience seclusion (O’Callaghan et al., 2021). While further progress can be made on these parameters, and there are undoubtedly differences between countries, this picture of psychiatry is markedly different to the one articulated by the WHO and OHCHR in their draft guidance – and markedly more protective of rights, including the right to appropriate mental health care.

Listening to mental health service-users and the evidence more generally

Perhaps the most concerning issue in the WHO/OHCHR draft *Guidance on Mental Health, Human Rights, and Legislation* related to ‘challenging and complex crisis situations’. The WHO/OHCHR noted ‘there is an aphorism in law that says, “hard cases make bad law”, which aims to convey the idea that highly unusual or difficult-to-solve cases are ill-suited to be used as the basis of general rules’:

However, in the field of mental health, it is common to present complex and challenging situations, often referred to ... as ‘hard cases’, as evidence that a total paradigm shift from substituted decision-making to supported decision-making is not possible, particularly in the context of mental health provision.

(pp. 62–63)

The occurrence of ‘hard cases’ does not, of course, suggest that a ‘paradigm shift from substituted decision-making to supported decision-making is not possible’, and it is a matter of regret that the WHO and OHCHR did not present evidence to support this statement.

But while a ‘paradigm shift’ is perfectly possible, ‘hard cases’ will still occur (even when best practice is followed) and will require solutions that are rooted in legislation, given the gravity of the issues involved. Saying that ‘hard cases make bad law’ does not prevent such cases occurring, does not assist with resolving them, and is not a reason to avoid dealing with them in guidance. The WHO/OHCHR continued:

These examples, regularly used in legal and clinical discussions, include cases where an individual is suicidal, the individual is behaving aggressively or violently, or when the individual is experiencing psychosis, or has intense support needs. The traditional medical framing of these cases as ‘hard cases’ fails to acknowledge that these complex and challenging situations are often the result of the failures of existing mental health systems, many of which are unable to adequately respond to trauma, distress and crisis.

(p. 63)

Again, stating that ‘hard cases’ are ‘often the result of the failures of existing mental health systems’ is true, and emphasises the need for better preventive health and social care. But saying this does not assist with resolving ‘hard cases’ when they occur, as they do, even in highly resourced, well-functioning systems. And nor is it a reason to avoid dealing adequately with ‘hard cases’ in guidance such as this. Regrettably, while the draft WHO/OHCHR document provided much information about good practice, it failed to provide sufficient guidance for occasions when ‘hard cases’ were not resolved by the good practice measures it outlined. This was a serious omission which will hopefully be addressed in future revisions.

The draft guidance stated that ‘if de-escalation fails and a situation of violence arises, crisis intervention teams could provide protection against interpersonal violence and support law enforcement to ensure the person is safely taken into custody where the person could be offered appropriate accommodations and support’ (p. 62). This suggested that, if good practice proved insufficient, it was better that ‘law enforcement’ take people with mental illness and disturbed behaviour into ‘custody’, rather than mental health professionals ensuring they go to health care settings where support and treatment are more likely to be available.

In essence, the draft guidance had clear difficulty dealing with the issue of violence. As a result, it avoided the issue when possible (on the basis that ‘hard cases make bad law’); outsourced the response to other sectors that are less skilled than mental health staff and would likely decline involvement anyway (such as ‘law enforcement’); and, on occasion, seemed to contradict itself. For example, the draft guidance suggested that ‘law enforcement’ might need to ‘ensure the person is safely taken into custody where the person could be offered appropriate accommodations and support’ (p. 62), but also stated that ‘police intervention’ should be ‘free from discrimination and any use of force or coercion’ (p. 97). The draft guidance did not explain how ‘law enforcement’ can keep a person in ‘custody’ without ‘any use of force or coercion’.

The root problem here is the ‘two cultures’. Clinicians deal with all kinds of issues (including ‘hard cases’) on a daily basis, are fully aware of the realities of care provision in imperfect systems, and, as a result, often find the WHO/OHCHR approach so far removed from reality as to be irrelevant. On the other side, the relentless and disproportionate criticism of psychiatry in these documents alienates mental health workers and enormously diminishes the impact of UN and WHO guidance, owing, not least, to their creation of a ‘biomedical’ strawman to support many of their more tenuous positions. This is a pity, because much needs to change in mental health services, generally (but not always) along the lines suggested by the UN and WHO.

The other causes of the ‘two cultures’ problem are a failure by the WHO and OHCHR to engage sufficiently with systematic evidence (including medical research, scientific studies, and reports about the realities of care provision); uncritical acceptance and selective quotation of statements by other UN bodies (creating an ‘echo chamber’ which amplifies questionable interpretations and positions); systematic neglect of the role of families, friends,

and communities in situations of mental distress; and a failure to reflect the true diversity of views among mental health service-users about such key concepts as capacity and treatment without consent (Freeman et al., 2015).

The latter point appeared to reflect a prioritisation of pre-existing ideology over evidence, and a more general tendency of UN bodies to reflect certain views of mental health service-users rather than others, as demonstrated by Gergel and colleagues in their study of service-users' views about self-binding directives:

The endorsement by the majority of service user respondents of involuntary treatment on the basis of impaired decision-making abilities counters a widespread view, upheld by the UN Committee on the Rights of Persons with Disabilities, that psychiatric use of capacity assessment and involuntary treatment necessarily violate fundamental human rights. Researchers, clinicians, and policy makers should consider that some service users with severe mental health conditions wish to request their own future involuntary treatment, using self-binding directives as a way to self-manage their illness and increase autonomy. When assessing the ethical viability of self-binding directives, mental capacity, and involuntary treatment, human rights advocates need to take a broad range of service user views into account.

(Gergel et al., 2021; p. 600)

Service-users' endorsement of 'capacity' is especially interesting in light of the view of the UN Committee on the Rights of Persons with Disabilities that 'mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity' (United Nations Committee on the Rights of Persons with Disabilities, 2014; p. 4). Precisely the same comments could be made about the word 'disability' which has been used to deny 'legal capacity' for even longer than 'capacity' has, but which the Committee appears to accept.

The draft WHO/OHCHR guidance echoed the Committee's views about 'capacity' and recommended 'an assessment of support needs' instead:

For example, during a crisis, assessing the person's support needs can help to determine if the person wants to go to an inpatient mental health service, a community crisis house, or simply be supported to stay at home.

(p. 67)

This appeared to be asking someone about their preferences, which is vital but is not 'an assessment of support needs', and so it did not provide significant assistance if the concept of 'capacity' is to be jettisoned. The UN Committee on the Rights of Persons with Disabilities seems clear that it does not feel a responsibility to provide an alternative to 'capacity' in order to assess 'support needs':

The provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity.

(p. 7)

The Committee does not specify who should develop such ‘non-discriminatory indicators of support needs’ or what they might be. This omission raises an ethical concern about issuing vetoes but assuming no responsibility to suggest alternatives.

This issue was also apparent in the draft WHO/OHCHR document which sought to veto ‘all involuntary measures’ (p. 61). The WHO and OHCHR made this draft recommendation despite the facts that (a) ‘no country has yet eliminated all forms of coercion in mental health systems’ (p. 61) (and therefore it might not be possible); (b) ‘sometimes there will be no optimal solution’ (p. 65) (which are precisely the times when guidance is needed); and (c) its guidance on dealing with ‘hard cases’ in the absence of involuntary care was a mixture of repeating good practice measures which are often used already (pp. 63–64), avoiding difficult questions that arise when such measures do not work (on the basis that ‘hard cases make bad law’; p. 62), outsourcing the response to a less experienced sector (‘law enforcement’; p. 62), and making a deeply puzzling recommendation about a person being taken into ‘custody’ by ‘law enforcement’ (p. 62) without ‘any use of force or coercion’ (p. 97).

Issuing these kinds of vetoes without suggesting meaningful alternatives that address complex situations is deeply unhelpful. These are difficult circumstances, but that is precisely why guidance is needed. Broader, deeper engagement with mental health service-users, families, community leaders, and service-providers would help generate more useful guidance, protect rights, promote mental health, and support people through crises. Hopefully, more developed versions of the WHO/OHCHR guidance will address these matters. Avoiding difficult questions does not help anyone and can undermine the right to health in a population with especially complex needs.

The right to involuntary care

The issue of admission and treatment without consent is, perhaps, the most difficult question in this field and – again – highlights the ‘two cultures’ problem.

In 1990, H. Richard Lamb wrote about ‘involuntary treatment for the homeless mentally ill’ in the *Notre Dame Journal of Law, Ethics and Public Policy*. Lamb concluded by painting a picture that is familiar to many people with mental illness, their families, their friends, and mental health workers all around the world:

Suppose I were acutely or chronically psychotic to the point of incompetency to make a decision about treatment and were living on the streets, vulnerable to every predator, eating out of garbage cans, and in and out of jail. I would fervently hope that the agent of society who saw my plight would not simply tell me that I have a right to live my life that way but instead would do something to rescue me – ‘against my will’ if necessary. Society owes us that much.

Thus, the mentally ill have another crucial right. When, because of severe mental illness, they present a serious threat to their own welfare or that of others and at the same time are not able to ask for or even to accept treatment, they have a right to involuntary treatment. Not to grant them that right is inhumane.

(Lamb, 1990; p. 280)

That passage was written in 1990, before the UN *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care* (United Nations, 1991),

before the CRPD (United Nations, 2006), and before the draft WHO/OHCHR recommendation that ‘legislation should clearly prohibit all involuntary measures’ (p. 61).

Notwithstanding this most recent draft recommendation, the need for treatment without consent at certain times was and still is broadly and consistently recognised today, as it was in Lamb’s time. Not only has ‘no country ... yet eliminated all forms of coercion in mental health systems’, as the WHO and OHCHR pointed out in their draft guidance, but in 2014, eight years after the CRPD, the UN Human Rights Committee outlined conditions under which it considers deprivation of liberty to be acceptable:

The existence of a disability shall not in itself justify a deprivation of liberty but rather any deprivation of liberty must be necessary and proportionate, for the purpose of protecting the individual in question from serious harm or preventing injury to others. It must be applied only as a measure of last resort and for the shortest appropriate period of time, and must be accompanied by adequate procedural and substantive safeguards established by law. The procedures should ensure respect for the views of the individual and ensure that any representative genuinely represents and defends the wishes and interests of the individual.

(UN Human Rights Committee, 2014; paragraph 19)

The WHO and OHCHR could usefully include this wording in the final version of their guidance about mental health legislation, limiting deprivation of liberty to certain, defined circumstances, with rigorous oversight. Simply hoping that a renewed emphasis on good practice and support will prevent all ‘hard cases’ and completely remove the need for treatment without consent and substitute decision-making is not evidence based, realistic, or protective of rights.

There has been no stage in human history when some people with mental illness were not severely ill to the point of refusing care, excluded from society, homeless, and profoundly neglected (Kelly, 2022). Hopefully, ours will be the first generation in history to develop services to a degree that prevents all such cases, but, in the meantime, we need to consider those who suffer *today*, many of whom see the need for treatment without consent themselves, from time to time (Freeman et al., 2015; Gergel et al., 2021). Their voices matter.

In 2016, two years after the UN Committee on the Rights of Persons with Disabilities issued its ‘General Comment No. 1’, the UN Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment endorsed the need for treatment without consent under limited, specific circumstances, and agreed with Lamb (Lamb, 1990; Lamb, 2000) that denying such treatment could amount to a denial of rights:

14. Exceptionally, it may be necessary to medically treat a person deprived of liberty without her or his consent if the person concerned is not able to: (a) Understand the information given concerning the characteristics of the threat to her or his life or personal integrity, or its consequences; (b) Understand the information about the medical treatment proposed, including its purpose, its means, its direct effects and its possible side effects; (c) Communicate effectively with others.
15. In such a situation, the withholding of medical treatment would constitute inappropriate practice and could amount to a form of cruel, inhuman or degrading treatment or punishment. It may also constitute a form of discrimination. The measure must be

a last resort to avoid irreparable damage to the life, integrity or health of the person concerned, and must be mandated by a competent authority within a strict framework that sets out the criteria and duration for the treatment and review and supervision mechanisms.

(UN Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, 2016)

Again, this is wording that the WHO and OHCHR could usefully incorporate into their final guidance on mental health legislation, acknowledging that ‘hard cases’ occur and providing guidance for those situations, while also including material about best practice, promoting a paradigm shift to supported decision-making, and articulating a goal of zero-coercion in mental health care – although these goals should not be met at the expense of the minority of people who need treatment without consent or substitute decision-making for periods of time. *Everyone* matters.

More broadly, the WHO and OHCHR could usefully recognise that while an emphasis on individual rights such as the right to health care is urgently needed, individual legal ‘rights’ are not the only or even the best way to articulate and meet certain human needs (Osiatyński, 2009). There is growing recognition that legal intervention, although necessary, will have limited impact on addressing stigma or achieving global access to care and support (Petrila, 2010; Glover-Thomas and Chima, 2015). An exclusive focus on individual rights also fails to recognise the complexity of how socialisation influences personal autonomy (Kong, 2017). In addition, access to litigation is not equally distributed to all (Donnelly, 2010).

Notwithstanding these caveats, individual rights still matter hugely and have been shamefully neglected in health systems (Bartlett, 2010). The CRPD offers a valuable opportunity to address this issue and promote the right to mental health care, but the interpretation of the CRPD by the UN Committee on the Rights of Persons with Disabilities may well end up hurting the very people the CRPD purports to help (Appelbaum, 2019). Regrettably, that interpretation was echoed throughout the WHO/OHCHR draft guidance on mental health legislation and, as a result, potentially undermined the right to health for many people with serious mental illness.

Conclusions

In 2018, India commenced a new piece of mental health legislation, the Mental Healthcare Act, 2017. India’s legislation states that it was designed to comply with the CRPD, but includes admission without consent (section 89) and substitute decision-making (section 89(7)), both of which are inconsistent with the UN Committee on the Rights of Persons with Disabilities’ interpretation of the CRPD (United Nations Committee on the Rights of Persons with Disabilities, 2014).

The Indian legislation, however, also includes ‘a right to access mental healthcare and treatment’ (section 18(1)) and various other progressive measures that are highly consistent with the CRPD itself (Kelly et al., 2020). In addition, the 2017 Act recognises that articulating an individual legal right is not enough: the Act also commits the Indian government to providing sufficient mental health services (section 18) and human resources to make the system work (section 31), notwithstanding the considerable problems that Indian mental health services face (Gautham et al., 2020).

Despite the inevitable challenges of this undertaking, the Indian legislation takes a pragmatic approach to the CRPD and provides an explicit right to mental health care. The inclusion of measures relating to accommodation and community rehabilitation within this right (section 18(4)) acknowledges the social factors that shape mental illness, care, and outcomes, as the WHO and OHCHR also pointed out in their draft guidance:

Mental health cannot be considered in isolation of an individual's multiple and intersecting layers of identity and oppression. A person's age, sex, sexual orientation, gender identity, disability, caste, racial or ethnic origin, socio-economic status, migrant or refugee status, and other markers of identity and experience cumulate to influence mental health and access to quality mental health care and support.

(p. 15)

Later, when discussing 'hard cases', the WHO and OHCHR add that:

the traditional medical framing of [certain] cases as 'hard cases' fails to acknowledge that these complex and challenging situations are often the result of the failures of existing mental health systems, many of which are unable to adequately respond to trauma, distress and crisis.

(p. 63)

Psychiatry, of course, has recognised the roles of systems of care and socio-economic factors in shaping mental distress long before the UN and WHO existed (Blazer, 2005).

Today, psychiatrists and many others continue to highlight the structural inequalities, socio-economic circumstances, and system failings that shape the landscape of risk for mental illness and psychological distress, how they are diagnosed and treated, whether people are supported appropriately, and what the outcomes are (see, for example, Kelly, 2005; Burns, 2013a; Burns, 2013b; Torrey, 2014; Kelly, 2022). It is a matter of satisfaction that the WHO and OHCHR have also come to recognise these factors as significant. Achieving social justice (Callard et al., 2012) and protecting human dignity are key roles for mental health services and legislation (Kelly, 2016), along with preventing and treating mental illness. These should be priorities for mental health legislation and should be duly reflected in guidance.

With this in mind, and notwithstanding useful descriptions of good practice in the draft WHO/OHCHR guidance, it was a matter of regret that the draft guidance did not adequately address the most difficult situations that occur even in well-resourced systems. These include occasions when supported decision-making is not enough or when treatment without consent is unavoidable. As the WHO and OHCHR pointed out in their draft document, a paradigm shift needs to occur towards supported decision-making, and all countries need to implement coercion-reduction programmes with the goal of zero coercion, but as long as the WHO/OHCHR recommendations avoid dealing adequately with difficult situations, they will remain just one side of the 'two cultures' problem, alienated from service-providers and many mental health service-users.

Hopefully, the final WHO/OHCHR guidance will improve on the original draft and recognise that 'hard cases' will still occur and require guidance. There will be occasions when, notwithstanding best efforts and good practice, a person's will and preference will not be ascertainable for periods of time. There will be occasions when, despite best efforts and good practice, treatment without consent is needed for periods of time, at least until (and if) men-

tal health services are transformed along the lines outlined by the WHO and OHCHR. Even then, it is not known if these difficult situations will be entirely eliminated, will become less common, or will simply be dealt with by ‘law enforcement’ (p. 62), with inevitably greater emphasis on ‘custody’ rather than care.

As a result, it was a matter of great concern that the draft guidance from the WHO and OHCHR recommended prohibiting substitute decision-making (p. 47) and treatment without consent (p. 61), and then noted that ‘sometimes there will be no optimal solution’ (p. 65). These are the precise occasions when guidance is needed most – difficult situations in which optimal solutions are elusive.

It was also gravely concerning that the draft guidance said that ‘if de-escalation fails and a situation of violence arises, crisis intervention teams could provide protection against interpersonal violence and support law enforcement to ensure the person is safely taken into custody where the person could be offered appropriate accommodations and support’ (p. 62). The idea of ‘custody’ appears inconsistent with the later statement that ‘police intervention’ must be free from ‘any use of force or coercion’ (p. 97). This issue will hopefully be resolved in the final document, but even its appearance in a draft for consultation presents real cause for concern.

Ultimately, it is vital that any paradigm shift takes account of *all* service-users’ needs – those of the majority, whose needs will be met through good practices outlined by the WHO and OHCHR, and those of the minority, who will require substitute decision-making or treatment without consent for periods of time. Hoping that a paradigm shift which has yet to occur will eliminate all such cases is not an evidence-based way to proceed. As the WHO and OHCHR pointed out in the draft guidance, no country has managed to entirely eliminate coercion from mental health care (p. 61). It is reasonable to hope that such a thing is possible, but hope is not a strategy.

As a result of these issues, the draft WHO/OHCHR guidance did not protect the right to mental health care for many people, and, as originally written, would have worsened the ‘two cultures’ problem by failing to reflect ‘the endorsement by the majority of service user respondents of involuntary treatment on the basis of impaired decision-making abilities’ (Gergel et al., 2021; p. 600). The CRPD is clear that ‘persons with disabilities’ must receive ‘the same range, quality and standard of free or affordable health care and programmes as provided to other persons’ (United Nations, 2006; article 25(a)). The draft guidance, as originally written, would have undermined this right for people with severe mental illness.

Just as no one would deny social, medical, or surgical care to persons with impaired decision-making ability, legislation must ensure that all approved mental health treatments, ranging from psychotherapy to medication, are available to all who need them. For people whose ability to decide is impaired for periods of time (e.g., owing to severe mental illness), additional safeguards are needed in legislation, but the complexity of these situations should not be used as an excuse to avoid dealing with them or to simply state that ‘sometimes there will be no optimal solution’ (p. 65). Guidance is an opportunity to create solutions, not admit defeat. A failure to address these issues in the final guidance would be a profound failure to protect the equal right to care.

In summary, a paradigm shift towards supported decision-making should occur, as suggested by the WHO and OHCHR in their draft guidance, but should be studied closely (to ensure it works) and should not occur at the expense of the minority of people whose needs are not met, and whose rights are not protected, by this approach. One size does not fit all. Everyone matters, including people whose wills and preferences cannot be clarified

for periods of time (even with extensive support) and people who require treatment without consent for periods of time (despite best practice at earlier stages in their care). These situations will hopefully be rare, short-lived, and managed in such a way as to respect rights – but these situations will continue to occur. Simply hoping that they will not happen is unrealistic and unhelpful for people who face these problems. Legislative guidance is needed to support their wellbeing and rights.

The WHO/OHCHR guidance should retain the goal of zero-coercion in mental health care, but should also retain admission and treatment without consent under very limited circumstances, using wording outlined by the UN Human Rights Committee (2014) and UN Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (2016) (above). This issue is too important to avoid in guidance or to omit from law.

The matter of issuing a veto on involuntary care (p. 61) without providing an adequate alternative was also addressed by the Bureau of Mental Health Policy of the Ministry of Health and Welfare of the Republic of Korea, in their response to the WHO/OHCHR draft:

As mentioned in the draft guidance, a zero-coercion policy requires developing a non-coercive approach and its implementation manual, which can address difficult circumstances case by case. This zero-coercion policy needs to be supported by a relevant system and workforce to make it actually work in mental health institutions. It would therefore be very helpful if the WHO-OHCHR guidance provides some guidelines on how the government can commit by law to this zero-coercion policy. Similarly, more effective guidelines are also needed on the requirements of crisis support services to better implement these services without any coercive actions in emergent situations.⁵

On the other side of the ‘two cultures’ problem, clinicians need to engage more with the development and operation of guidance from the WHO, OHCHR, and UN more generally. Such guidance will remain detached from the realities of care provision unless service-providers participate in its development and operation. In this spirit, I submitted many of the points made in this chapter to the WHO and OHCHR during the consultation period about their draft guidance, in the hope of informing their final document.⁶

Addressing the ‘two cultures’ problem in the longer term will require a multi-pronged approach, including more inter-disciplinary research and enhanced collaboration in planning and delivering care. In 2022, the WHO published a document titled *World Mental Health Report: Transforming Mental Health for All* (World Health Organization, 2022) focusing on the need to transform services along these lines. Updating mental health legislation is a key part of this process and a vital way to advance the right to mental health care. The 2022 draft WHO/OHCHR guidance on mental health, human rights, and legislation made a good start, but also had significant problems that required resolution in order to advance the right to mental health care for all, equally and without discrimination. This issue is simply too important to get wrong.

5 https://www.ohchr.org/sites/default/files/documents/issues/health/draftguidance/submissions/2022-08-16/Min_health_welfare_rep_korea_response.docx (Accessed 28 February 2023).

6 https://www.ohchr.org/sites/default/files/documents/issues/health/draftguidance/submissions/2022-08-30/B_kelly_trinity_college_ireland_response.docx (Accessed 28 February 2023).

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