

Introduction

A “Paradigm Shift” in Mental Health Care

*Faraaz Mahomed, Michael Ashley Stein, Vikram Patel,
and Charlene Sunkel*

Abstract

The passage of the United Nations Convention on the Rights of Persons with Disabilities (CRPD or the Convention) has been hailed as the culmination of a “paradigm shift” from the biomedical model of disability to the social and human rights-oriented model. The CRPD’s assertion of equal recognition before the law applying to all persons with disability, including mental health and psychosocial disability, and thus amounting to universal legal capacity, in Article 12 and in the subsequent General Comment, Number 1 on Article 12 issued by the Committee on the Rights of Persons with Disabilities (CRPD Committee), has been the subject of considerable debate. While many have argued that this is a long overdue protection and a manifestation of nondiscrimination and freedom from coercion on the basis of disability, some have raised concerns based on perceived impracticality or risk. Among the obligations of States parties to the Convention is the mandate to shift from coercion, in the form of substitute decision-making models, to supported decision-making regimes, relying on a “will and preference” standard rather than a “best interests” standard. Even while debate around the exact nature and scope of Article 12 and General Comment 1 continues, efforts to end coercion in mental health and to promote supported decision-making have been gaining momentum in laws, policies, and practices around the world.

1 INTRODUCTION

The CRPD is an extraordinary instrument that potentially has unprecedented implications for social, economic, political, and legal systems as well as for practitioners in policy, health, education, and numerous other fields. Mental health law, policy, and practice are particularly affected by the need to domesticate the provisions of the CRPD into national frameworks. For example, the Indian Mental Health Care Act of 2017 (Ministry of Law and Justice, 2017) states explicitly that it was drafted because “it is necessary to align and harmonise the existing laws with [the CRPD].” Indeed, similar processes have taken place, or are in motion, in various corners of the world, ranging from Scotland to Colombia, Kenya, Ghana,

Hungary, Ireland, Zambia, Costa Rica, Peru, Northern Ireland, and parts of Canada and Australia (El Congreso de Colombia, 2019; Kenya National Commission on Human Rights, 2018; Hoffman and Könczei, 2010; Department of Justice and Equality, 2013; Disability Rights Watch, 2015; Disability Rights Fund, 2012; ASAN, 2016; Asamblea Legislativa de la Republica Costa Rica, 2016; Australian Law Reform Commission, 2017; Northern Ireland Human Rights Commission and Equality Commission for Northern Ireland, 2017; see also Chapter 9 by Faisal Bhabha, Chapter 11 by Adrian D. Ward, and Chapter 12 by Heléne Combrinck and Enoch Chilemba).

In 2017, the United Nations (UN) Special Rapporteur on the rights of persons with disabilities reported that at least thirty-two countries had either undertaken reforms or were in the process of implementing reforms to their legal frameworks to incorporate the paradigm advanced by the CRPD (UN General Assembly, 2017b). It is indeed worth highlighting these examples as indicating the very significant potential for change that has arisen in the aftermath of the adoption of the CRPD. Notwithstanding this potential, however, challenges remain in realizing the CRPD's provisions to its fullest extent. In this respect, one particular topic is repeatedly cited as a challenge: the issue of acknowledging and implementing legal capacity for people with psychosocial disabilities.¹ In this chapter, we outline the provisions related to legal capacity in the CRPD, while also examining the controversies that have arisen related to these provisions and the continuing impediments to implementation thereof.

2 THE CRPD AS A CULMINATION OF A “PARADIGM SHIFT”

The CRPD was adopted by the UN General Assembly in 2006 and, at the time of writing, has gained 181 State ratifications. The Convention has been credited with shifting the manner in which disability rights are conceived of and operationalized.

¹ In practice, the evolving debates around legal capacity also apply to what are often referred to as intellectual or cognitive disabilities and some degenerative conditions, such as dementia. Intellectual and cognitive disabilities are distinct from psychosocial disabilities in that the etiology of the former is primarily related to biological determinants and the disability is evident from birth or early life and endures throughout the life of the person; on the other hand, the etiology of the latter is thought to derive from an interaction of psychological and environmental factors with biological factors; the disability appears most commonly during one's youth; and it is often not enduring. Dementia, which typically begins in older age and is a progressing neurodegenerative condition, has multiple biological etiologies ranging from vascular incidents to Alzheimer's disease, and does significantly alter the ability of an individual to function independently. All of these conditions are likely to be affected by changes in decision-making regimes and should, therefore, be considered in debates related to legal capacity. In practical terms, this was not possible for this particular book; as a result, the book focuses on psychosocial disabilities. That being said, it is conceivable that many of the findings and assumptions relating to mental health may apply to intellectual disabilities, dementia, and other conditions which affect capacity. However, this is not a universal truth, and conclusions drawn here about the mental health care system should be interrogated further before being applied to social care models for the intellectually disabled or for those whose condition may not improve with time.

It is the first treaty of its kind and one of the most widely ratified international conventions in history, illustrative of a broader “paradigm shift” from an impairment-focused, “biomedical” model to a socially-oriented, human rights-focused model (Stein and Lord, 2010; Pearl, 2013). The former view suggests that disability is an individual impairment, a function of the organic deficit or illness in a particular person, which can be addressed largely through a medical intervention. More recent iterations of this model have, however, incorporated critical elements and made mention of the need to address various social determinants that cause or exacerbate mental health challenges. Nonetheless, critics argue that its primary emphasis remains a focus on a biomedical conceptualization of “illness” (Deacon, 2013).

The social model views disability as a product of an individual’s interaction with his or her environment. The impairment is the result of a lack of an accommodating environment and the “disability” is actually a result of a context which denies a differently abled person the same rights and opportunities afforded to others (Shakespeare, 2006). While the social model is seen as a useful explanatory model for disability, it has been critiqued for not offering substantial guidance for how to go about changing circumstances that marginalize people with disabilities. Moreover, the needs for disability to be valued as a facet of human diversity and for social justice to be a cornerstone of thinking around disability were highlighted as important shortcomings that later came to be addressed through the human rights-based model embodied by the CRPD (Stein, 2007). It is these shifts in thinking – and the requirement that these shifts also see realization in law and policy – that have led authors to view the CRPD as the culmination of a “revolution” in disability discourse (Pearl, 2013).

The relationship between human rights-based approaches and biomedical or public health approaches to mental health has brought into view some inherent tensions, with even the terminology of “mental illness” being critiqued and replaced by the CRPD-informed construct of psychosocial disability. Differing approaches to psychosocial disability or mental health can influence policies, interventions, and potentially even public attitudes (see also Chapter 1 by Alicia Ely Yamin). By its nature, mental health interacts with various disciplines that include psychiatry, psychology, public health, anthropology, economics, law, and public policy. These disciplines and their practitioners face the daunting task of interpreting and implementing the paradigm shift alluded to above, while also incorporating various discipline-specific objectives and ethical considerations.

3 LEGAL CAPACITY THEN AND NOW: THE SIGNIFICANCE OF ARTICLE 12 OF THE CRPD

Since the adoption of the CRPD, the area that has arguably spurred the most considerable debate is around the issue of legal capacity, or the capacity to be

recognized as a “legal person” before the law, incorporating both the holding of rights and duties (legal standing) and the actual exercise those rights and duties (legal agency). The recognition (or lack thereof) of legal capacity can have important implications, including affecting the right of people living with psychosocial disabilities to make decisions about treatment, to live independently, to vote, and to enter into contracts (Dhanda, 2006). Traditional approaches to capacity have been rooted in millennia-old conceptions of mental health challenges as spiritual deficits, with resultant practices of chaining, exorcism, incarceration, and sometimes even execution, with decision-making based largely on the judgments of spiritual or religious counselors or medical practitioners of the day (Kroll and Bachrach, 1984). With the movement to the “illness” theory of etiology of mental health conditions evident in the development of the biomedical model, many of these practices were somewhat reified, allowing for what is now known as “substitute decision-making” or the judgment of a clinician or family member or other judicially recognized individual to supersede that of the person affected when that person is deemed to be incapacitated due to their mental state (Ossa-Richardson, 2013; Dunn et al., 2005). This has led to a history of numerous forms of abuse and maltreatment. At the onset of the CRPD negotiations, the World Network of Users and Survivors of Psychiatry demonstrated that a wide range of unnecessary and harmful coercive measures have been implemented at the hands of professionals in whose power resided the adjudication of an individual’s “competence” to make decisions for themselves, in the process suggesting that coercive treatment amounts to a violation of the right to freedom from torture and cruel, inhumane, and degrading treatment (World Network of Users and Survivors of Psychiatry, 2001; see also Chapter 3 by Tina Minkowitz), a position later also adopted by the UN Special Rapporteur on torture (United Nations General Assembly, 2013).

In large part because of the history of the abuse of declarations of incapacity, and because of the discriminatory nature of laws that discriminate against people with psychosocial disabilities (sometimes referred to as “sanism;” see Perlin, 1992), the global disability rights movement has been vocal in its campaign for the right to equal recognition before the law, a campaign which was successful in the drafting of Article 12 of the CRPD. Paragraph 2 of Article 12 provides that:

States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life . . .

This provision is viewed by many as a crucial tool to end discrimination on the basis of psychosocial disability, and a key achievement of the CRPD (Arstein-Kerslake and Flynn, 2016).

Further interpretation of Article 12 takes the form of General Comment 1 on Article 12 by the CRPD Committee, issued to clarify the scope and application of Article 12 (CRPD, 2014). The General Comment asserts that equal recognition before the law, and, by extension, legal capacity, are universally applicable rights

which cannot be derogated because of a disability. The Committee further recognizes the right to supported decision-making where necessary and requires state parties to the CRPD to eliminate substitute decision-making with immediate effect. It is important to note that the General Comment states explicitly that the principle of progressive realization does not apply to the issue of legal capacity. It therefore obligates States to roll out supported decision-making mechanisms and to engage in law reform without delay (see Chapter 5 by Laura Davidson). Yet, as demonstrated below, it is not without its detractors.

4 OPPOSITION TO THE ADOPTION OF ARTICLE 12

According to the UN Special Rapporteur on the rights of persons with disabilities, thirteen countries² “issued reservations and declarations upon ratification or accession, with the intention of limiting the implementation of Article 12 and other related articles” (United Nations General Assembly, 2017b: 9–10). Germany and Norway argued that it is not contrary to the CRPD to restrain legal agency when a person cannot make a decision in their own interests, even in the event of the best possible support being made available, because such an action does not diminish legal standing (Federal Republic of Germany, 2014; Government of Norway, 2014). Similarly, Denmark and France suggested that, while legal standing is an absolute and universal right, legal agency can be restrained when necessary (Ministry of Foreign Affairs of Denmark, 2014; République Française, 2014; see also Chapter 23 by Dorrit Cato Christensen). This goes to show, then, that there has been substantial controversy regarding the right to equal recognition before the law since the very inception of the CRPD.

Article 12 of the Convention and General Comment 1 have, moreover, been criticized as potentially damaging flaws in the treaty (Ward, 2011; Freeman et al., 2015; Appelbaum, 2016), with some even calling for revisions to the treaty (Appelbaum, 2019). A particular controversy exists with regard to involuntary treatment and with respect to the implications for people living with psychosocial disabilities. Clinicians have argued that, as key participants in the implementation of any provisions relating to the care, support, and treatment of people living with psychosocial disabilities, sufficient consultation and engagement did not take place (Freeman et al., 2015). A universalist approach to legal capacity has been argued to be unhelpful because of the ethical difficulties visited upon clinicians who have a duty to protect mental health care users who might be considered vulnerable and because of the potential for abuses at the hands of “supporters” (Ward, 2011; Scholten and Gather, 2017; Weich, 2017). While the General Comment requires State parties to the CRPD to adhere to these principles, it does not offer substantive guidance on how States can harmonize their laws, including mental health laws, with its thinking.

² Australia, Canada, Egypt, Estonia, France, Georgia, Kuwait, Malaysia, Netherlands, Norway, and Poland, Singapore and Venezuela (Bolivarian Republic of).

The General Comment mandates that supportive regimes become a standard feature of systems which interact with people living with psychosocial disabilities, prioritizing the will and preference of the individual concerned as opposed to the traditional “best interests” standard that critics of a biomedical approach have argued can be construed as paternalistic (Browning, Bigby, and Douglas, 2014). In instances where that will and preference is unknown, States should require adherence to the “best interpretation of the individual’s will and preference.” Dhanda (2017), for example, notes that legal capacity is intrinsically linked to personhood, because it is through one’s ability to act autonomously that they are able to exercise their personhood. Other scholars, still, have argued that the suggestion that a right such as dignity is derived from capacity or that personhood is dependent on autonomy is, itself, flawed, because dignity, personhood, and equality are derived from humanity alone (Bilchitz, 2016). Whether this can satisfy mental health service users who view “legal control” as a central feature of their own dignity is, however, a complex question (Kogstad, 2009).

Some clinicians and legal scholars, while not questioning the content of the right articulated in the CRPD, have questioned whether this vision of legal capacity can be realized in practical terms, because of the difficulty – and perhaps even the impossibility – of reaching a best interpretation of every patient’s will and preference; commentators have suggested that there will always be some individuals for whom such an interpretation cannot be elicited – so-called “hard cases” (Quinn, 2010; Dawson, 2015; Gooding, 2015; see also Chapter 18 by Piers Gooding). Others consider universal legal capacity as the possible dereliction of the duty to protect people living with psychosocial disabilities from maltreatment, neglect or exploitation (Dawson, 2015; Scholten and Gather, 2017), citing examples such as mania or rare cases of violent psychosis, or women with mental health challenges who live on the street (see Chapter 7 by Ravi et al.). Detractors of the CRPD approach have also argued that there is a moral or ethical duty to engage in coercive mental health interventions when the person with a psychosocial disability might pose a risk of harm to self or others (Scholten and Gather, 2017). Defenders of the CRPD position, however, have suggested that a reluctance to relinquish power over the lives of those affected is a significant driving factor behind these concerns, and suggest that this power, which has undoubtedly been left open to abuse, requires urgent and systematic checking if the abuses of the past are not to be repeated (Spandler, Anderson, and Sapey, 2015; Series, 2015). Similarly, defenders of the CRPD approach also note that the “risk of harm” argument, when applied solely to people with psychosocial disabilities, constitutes unfair discrimination on the grounds of disability (Callaghan, Ryan, and Kerridge, 2013; in this volume, see also Chapter 4 by Gerald L. Neuman and Chapter 8 by Alberto Vásquez Encalada). Others argue also that diagnoses of mental health conditions and concomitant involuntary treatment are themselves applied disproportionately to marginalized groups, thus reflecting systemic and structural barriers to equality that coercion only exacerbates

(Bennewith et al., 2010; see also Chapter 22 by Lydia X. Z. Brown and Shain M. Neumeier).

Linked to the debate regarding involuntary treatment is also the debate regarding the so-called “insanity defense,” which would, according to some commentators, be considered untenable if universal legal capacity were to be operationalized. While the claim of universal legal capacity can go some way to addressing the stigmatization of psychosocial disabilities in criminal justice systems, some authors question whether it leaves those affected vulnerable to abuse and amounts to a violation of due process, fair trial, and dignity mandates. Michael Perlin (2015) argues that this represents an oversight of the drafters, in that the implications of universal legal capacity never discussed this particular challenge, suggesting that it may have been an unintended consequence of the broader shift towards universal legal capacity. However, the General Comment (2014) is clear on the need for criminal law to be “disability-neutral,” thereby precluding a defense based on disability status. Others have argued that the defense of inability to judge the rationality of one’s own actions need not be based on disability but, instead, criteria ought to be applied which are suitable for disabled and non-disabled alike (Slobogin, 2014). It is therefore worth noting that questions which apply to treatment bear significance for this realm of criminal justice as well.

5 WHAT NOW? (NON)IMPLEMENTATION OF ARTICLE 12 AND GENERAL COMMENT 1

Some 181 States parties are bound by the provisions of the CRPD, and many have already begun the process of seeking to ensure its domestication into national laws and policies, including those relating to mental health. Yet, despite the desire to see this “new” paradigm gain traction, there remain significant questions about how the provisions of the CRPD and General Comment 1 to Article 12 can be implemented, even among proponents of the universalist approach to legal capacity (Szmukler, Daw, and Callard, 2014; Dhanda, 2017; see also Chapter 6 by John Dawson and George Szmukler). Numerous scholars, generally supportive of the paradigm of supported decision-making, have nonetheless raised questions about the need for exceptions or nuanced interpretations that take into account the proportionality of a particular disability and accommodate interventions to avoid “serious adverse effects” (Bach and Kerzner, 2010) or to address the risk of “imminent and grave harm” (De Bhailis and Flynn, 2017). Yet it has been noted that these very exceptions then reawaken the possibility of abuse and maltreatment that Article 12 and General Comment 1 were intended to put an end to (Dhanda, 2017). Likewise, calls for a “radical reduction and eventual elimination” of coercive treatment, including by the UN Special Rapporteur on the right to health (United Nations General Assembly, 2017a; see also Chapter 2 by Benjamin A. Barsky, Julie Hannah, and Dainius Pūras), have been viewed as insufficient by those seeking complete

abolition on the basis of its potential for abuse and because it is seen as the gradual implementation of a step that ought to be taken without any reservations or equivocations (Minkowitz, 2017).

The literature in recent years has shown that these questions remain largely unresolved, despite the obligations incumbent upon state parties to domesticate the CRPD (Gooding, 2015; Dhanda, 2017; Series, 2015). Laws that have been enacted since the issuance of the CRPD and General Comment 1 have struggled to find a balance between the call for supported decision-making regimes and established clinical, legal, and social practices. In 2016, Costa Rica adopted Law No. 9379, which abolished all forms of guardianship and created the legal figure of “guarantor for the equality before the law of persons with disabilities,” whose role is to ensure the full enjoyment of legal capacity by all persons with disabilities; but appointment of a guarantor is itself dependent on the adjudication of a court (United Nations General Assembly, 2017b). In India, the Mental Health Care Act of 2017 allows for an advanced directive to be taken into account, although it may be applied when an individual is deemed to have “ceased” to have capacity (Ministry of Law and Justice, 2017), thus suggesting that the determination of capacity still relies on the judgment of a substitute (see Chapter 10 by Soumitra Pathare and Arjun Kapoor).

In Peru, strong advocacy from disabled people’s organizations led to reform of the civil code, which asserted the right to universal legal capacity (see Chapter 8). Even so, this instrument continues to allow exceptional pronouncements of incapacity, such as when an individual is deemed to be under the influence of a substance (Minkowitz, 2018). At the time of writing, the country is considering mental health legislation, parts of which have been determined to be in contravention of the CRPD (Personal communication with Alberto Vásquez Encalada, 2020). Similarly, provisions in the draft Kenyan Mental Health Amendment Bill and the draft Mexican Mental Health Amendment Bill have also been the subject of debate because they contain provisions which allow for substitute decision-making or because they fail to adequately implement supported decision-making (Health Rights Advocacy Forum, 2019; Human Rights Watch, 2017; see also Chapter 13 by Elizabeth Kamundia and Ilze Grobbelaar-du Plessis).

To counter the discriminatory application of incapacity law to people living with psychosocial disabilities as a group, others have sought broader attempts at “capacity legislation” that focuses not on the impairment per se but, rather, on the ability of individual to make a decision for him or herself, regardless of the reason for any perceived incapacity (Szmukler, Daw, and Dawson, 2010; see also Chapter 6). In keeping with this argument, the Northern Irish Mental Capacity Act provides a single legislative framework governing situations where a decision needs to be made in relation to the care, treatment (for a physical or mental illness), or personal welfare of a person aged sixteen or over, who lacks capacity to make the decision for themselves. The Act, assented to in 2016, continues to provide for substitute decision-making, while also requiring that an assessor or supporter pay “special regard” to the

individual’s past and present wishes and beliefs (Northern Ireland Human Rights Commission and Equality Commission for Northern Ireland, 2017).

Similar to the issue of laws and policies, clinical protocols and norms continue to grapple with the challenge of engaging health professionals on this subject of involuntary treatment. In 2016, the World Psychiatric Association (WPA) issued a Bill of Rights, in which it states:

When the patient is gravely disabled, incapacitated and/or incompetent to exercise proper judgment because of a mental disorder, the psychiatrists should consult with the family and, if appropriate, seek legal counsel, to safeguard the human dignity and the legal rights of the patient (cited in Lewis and Callard, 2017).

This is indicative of the fact that the CRPD’s thinking at the time did not necessarily align with that of the WPA, with potentially widespread implications for public health practice. The WPA published a ‘consultation paper’ in June 2020 entitled ‘Implementing Alternatives to Coercion in Mental Health Care’ in which states the following:

The passage of the . . . CRPD and subsequent statements from international human rights bodies have challenged nations worldwide to improve access to voluntary mental health supports and reduce, prevent and potentially even end coercive interventions. Some clinicians and other commentators have expressed reservations about (and in some cases, outright rejection of) moves to avoid coercion in mental health services. These include arguments that compulsory treatment must be available to protect individuals and/or those around them from harm, to protect individuals’ other rights, and to ameliorate the negative impacts of certain mental disorders on individuals’ wellbeing . . . These different views are reflected in debates by policymakers, government agencies and civil society organisations all over the world as well as among service users and persons with associated psychosocial disabilities. There is a risk that these debates are becoming intractable. What is often lost is the considerable agreement that exists across diverse perspectives, and the pathway that this creates for positive change. There is widespread agreement that coercive and compulsory practices are often over-used, and there is an evidence base to support the implementation of alternatives to coercion (World Psychiatric Association, 2020: 1).

This is perhaps a signifier that while the provisions of Article 12 and General Comment 1 continue to spur debate, the field of clinical practice is shifting substantially in favor of efforts to reduce or end coercion. In a similar vein, the World Health Organization (WHO) has developed a set of best practice guidelines under the rubric of the Quality Rights initiative, which states that all people possess legal capacity at all times, and which encourages States and healthcare practitioners to engage with efforts aimed at realizing the right to supported decision-making (WHO, 2017). The WHO has also invested significantly in capacity building for this model of care in various parts of the world, engaging with policymakers as well as

disability rights advocates (WHO, 2017). There is therefore some potential for reforming health systems in part through this initiative (see Chapter 16 by Funk et al.). Another source for optimism is the increasing proliferation of supported decision-making mechanisms in various parts of the world. This is the subject turned to next.

6 SUPPORTED DECISION-MAKING AND THE NEED FOR CONTEXTUALLY RELEVANT RESEARCH

Efforts to engage with supported decision-making have been gaining traction in various parts of the world. “Ulysses contracts,” or mental health advance directives, have pre-dated the CRPD in statutes or in practice in England, Wales, Scotland, Germany, the Netherlands, Switzerland, Austria, and parts of Canada (including in British Columbia, where advance directives are considered binding) and the United States, and have since been incorporated into such legislation as the Indian Mental Health Care Act (Ministry of Law and Justice, 2017; see also Chapter 10). These directives have demonstrated utility, but they also leave open the question of “which will” applies – that is, the contemporary preference or that contained in the directive, with ethicists noting that this remains an area that can be more opaque in practice than it seems in law and policy (Davis, 2008; Zelle, Kemp, and Bonnie, 2015; see also Chapter 6 and Chapter 11).

Peer support initiatives have also been gaining in popularity as alternative models of care that are user-driven and that meet CRPD standards (Pathare and Shields, 2012; see also Chapter 21 by Charlene Sunkel et al. and Chapter 17 by Joel D. Corcoran, Cindy Hamersma, and Steven Manning). In Britain, the “circle of support” model has been utilized to bring together groups of family members and friends of people living with psychosocial disabilities to engage with them on their will and preferences where needed (Circles Network, 2011). Similarly, the process of “open dialogue,” whereby mental health care users are treated in their own homes and dialogue is generated in family and treatment systems as a means of understanding the user’s experience (and, by extension, his or her preference), has been proposed as a potential solution, based on its demonstrated utility in Finland (Seikkula et al., 2006; see also Chapter 25 by Kanna Sugiura and Chapter 18). In Sweden, the introduction of a personal ombudsman for an individual with psychosocial disabilities has also been seen as a potential model, whereby the individual’s will is the primary consideration (National Board of Health and Welfare of Sweden, 2008; see also Chapter 15 by Ulrika Jarkestig Berggren). Likewise, a 2016 study investigated the utility of “crisis cards” as a means of documenting the treatment preferences of mental health care users, finding that such a method can be of utility if utilized regularly (Drack-Schonenberger et al., 2016).

Importantly, a review conducted in 2012 found that supported decision-making provisions were particularly wanting in low- and middle-income countries, raising