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## The World Psychiatric Association (WPA)

The WPA is an association of national psychiatric societies aimed to increase knowledge and skills necessary for work in the field of mental health and the care for the mentally ill. Its member societies are presently 140, spanning 120 different countries and representing more than 200,000 psychiatrists.

The WPA organizes the World Congress of Psychiatry every year. It also organizes international and regional congresses and meetings, and thematic conferences. It has 72 scientific sections, aimed to disseminate information and promote collaborative work in specific domains of psychiatry. It has produced several educational programmes and series of books. It has developed ethical guidelines for psychiatric practice, including the Madrid Declaration (1996).

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2. McRae TW. The impact of computers on accounting. London: Wiley, 1964.
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## Saving the UN Convention on the Rights of Persons with Disabilities – from itself

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) is a problem child of international human rights law. Like the girl with a little curl right in the middle of her forehead, immortalized in rhyme by H.W. Longfellow, when it's good, it's very, very good, and when it's bad it's horrid<sup>1</sup>. In embodying the rights of people with disabilities to accessibility, education, health, privacy, and other conditions likely to encourage their flourishing, the CRPD offers hope to people around the world whose disabilities have been the basis for their exclusion from the usual aspirations of life. However, in promoting restrictions in Article 12 on governments' abilities to intervene to protect the interests and rights of disabled persons, the CRPD – at least as interpreted by the UN Committee on the Rights of Persons with Disabilities (the Committee), set up to oversee its implementation<sup>2</sup> – may end up hurting the very people it purports to help.

As Szmukler notes in his thoughtful essay in this issue of the journal<sup>3</sup>, the CRPD is being interpreted by the Committee as precluding any involuntary intervention targeted at people with disabilities. Thus, under this view of the CRPD, elderly persons with dementia, no longer able to care for their own needs but unwilling to accept management of their finances, health, or living situations by a guardian, could not be compelled to do so. People intending to end their lives as a result of major depression could not be hospitalized against their will, nor could persons suffering from psychosis who are refusing to eat because they believe their food is poisoned. Someone in the manic stage of bipolar disorder would be free to dissipate his family's savings or wreck her business. In the name of protecting all these people from discrimination, they would be free to destroy their own lives and ruin the lives of their loved ones.

I have considered elsewhere how we arrived at this state<sup>4</sup>. In short, blame is due to a drafting process that was captured by some of the most radical elements of the patients' rights movement, which are willing to sacrifice the well-being of persons with disabilities to achieve what they see as their long-term political goals. It falls as well on the many governments around the world that thoughtlessly ratified the CRPD without considering its implications. Here, though, I want to focus on strategies for addressing the problems raised by the CRPD going forward. As best I can tell, there are three alternatives: ignore the CRPD, reinterpret it, or amend it.

Ignoring the CRPD, or at least those portions of it that are particularly problematic, might not seem like a viable alternative, given that the overwhelming majority of countries in the world – 177 at last count<sup>5</sup>, with the US a major exception – have ratified the document. In practice, however, that may not be the case. Szmukler cites a recent decision of the European Court of Human Rights which he characterizes as reinterpreting the CRPD, but which could equally well be considered simply to

have ignored Article 12 and its limitations. The court held that “The [appointment of a substitute decision maker for a person with intellectual disabilities] was proportional and tailored to the applicant's circumstances, and was subject to review by competent, independent and impartial domestic courts. The measure taken was also consonant with the legitimate aim of protecting the applicant's health, in a broader sense of his well-being”<sup>6</sup>. Along similar lines, as Dawson<sup>7</sup> notes, several countries ratified the Convention with reservations that would negate the more restrictive aspects of Article 12, or in their biennial reports have simply asserted that they were in compliance when they clearly were not.

Reinterpreting the CRPD in ways that differ from the approach taken by the Committee is another way of dealing with the problems. Those efforts have included arguments that protecting vulnerable people does not constitute discrimination – indeed, ignoring their vulnerability may be discriminatory<sup>4,7</sup>; that when rights protected by the CRPD are in conflict, e.g., preservation of life vs. exercise of legal capacity, the more important right should take precedence<sup>8</sup>; and that even the language of Article 12 itself appears to recognize that limitations on a person's decision-making power may be necessary<sup>7</sup>. Szmukler's analysis of the ways in which “will” and “preferences” – key terms in the CRPD – may be in conflict, and the logic in privileging sustained will over short-term preferences, falls into this category as well. In my view, all of these critiques of Article 12, which is a deeply flawed and internally inconsistent provision, are cogent. However, given the low probability that the Committee will be led by these critiques to change its interpretation, the arguments' efficacy will likely depend either on persuading states to ignore the counterproductive aspects of the CRPD or to pursue a more radical remedy, namely amendment of the CRPD.

Amending the CRPD may be the most effective long-term solution to the problems that so many governments and commentators have identified. It will not be an easy process. Drafting the CRPD required a roughly five-year effort, involving scores of non-governmental organizations and hundreds of individuals<sup>9</sup>. However, the CRPD itself (Article 47) envisions a less arduous process by which amendments can be made, allowing any state that is a party to the CRPD to propose an amendment, which can be considered with the support of one-third of states and adopted by a vote of two-thirds. Resistance can be anticipated from the Committee and the more radical parts of the disability rights movement that succeeded initially in capturing the drafting process; hence, success will depend on mobilization of governmental agencies, professional organizations, academics, family organizations, and disabled persons themselves to lobby their governments regarding the need for change. Only amending Article 12 can definitively reverse the extreme interpretation of the Committee and remove the

specter of international condemnation of any country that fails to comply with its approach.

Until that occurs, we can anticipate that governments and others responsible for the welfare of people rendered vulnerable by their disabilities will – and I would suggest should – ignore the Convention when it would interfere with a commonsense approach to protecting citizens who in one way or another are incapable of protecting themselves. For the future, the lesson to be learned is the critical importance of involvement of state representatives, professional organizations, and individual experts representing mainstream positions in the process of drafting crucial international documents.

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## “Capacity”, “best interests”, “will and preferences” and the UN Convention on the Rights of Persons with Disabilities

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*The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) is the most up-to-date international legal instrument concerning the rights of persons with disabilities. Such persons are taken to include those with serious mental disorders. According to an authoritative interpretation of a crucial Article (Article 12 - Equal recognition before the law) by the UN CRPD Committee, involuntary detention and treatment of people with mental health disabilities are prohibited under the Convention. Both conventional mental health law and “capacity-based” law are deemed to violate the Convention. However, some other UN bodies are not in full agreement (for example, the UN Human Rights Committee and the Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment), while others are less explicitly absolutist (for example, the Human Rights Council). Furthermore, strong criticisms of the position of the CRPD Committee have been mounted from a number of academic quarters. These criticisms center on whether the role of a person's ability to make a decision can be ignored, no matter the circumstances. Much of the above debate turns on the concept of “legal capacity” and the now often-repeated precept that one must always respect the “will and preferences” of the person with a disability. However, “will and preferences” remains undefined. In this paper, I offer an analysis of “will and preferences” that can clarify interventions that may be acceptable or non-acceptable under the terms of the UN Convention.*

**Key words:** UN Convention, human rights, persons with disability, UN CRPD Committee, mental disorders, involuntary treatment, mental health law, legal capacity, mental capacity, will, preferences, best interests, substitute decision-making

(*World Psychiatry* 2019;18:34–41)

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD)<sup>1</sup> is the most up-to-date international legal instrument specifically tailored to stipulate the rights of persons with disabilities. Such persons are taken to include those with serious mental disorders.

Recent authoritative interpretations issued by the UN Committee set up to monitor the implementation of the Convention (CRPD Committee) lead to an insistence that involuntary detention and treatment of people with mental health (or “psychosocial”) disabilities are prohibited.

For example, the Committee's General Comment No. 1 on Article 12 (Equal recognition before the law) of the Convention<sup>2</sup> includes the following statements:

“Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making.” (para. 17)

“States parties must review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-

making by supported decision-making, which respects the person's autonomy, will and preferences.” (para. 26)

“The denial of the legal capacity of persons with disabilities and their detention in institutions against their will, either without their consent or with the consent of a substitute decision-maker... constitutes arbitrary deprivation of liberty and violates articles 12 and 14 of the Convention.” (para. 40)

Furthermore, the Committee's Statement on Article 14 (Liberty and security of person) of the Convention<sup>3</sup> argues that:

“The Committee has called on States parties to protect the security and personal integrity of persons with disabilities who are deprived of their liberty, including by eliminating the use of forced treatment, seclusion and various methods of restraint in medical facilities, including physical, chemical and mechanic restraints.” (para. 12)

“The involuntary detention of persons with disabilities based on risk or dangerousness, alleged need of care or treatment or other reasons tied to impairment

or health diagnosis is contrary to the right to liberty, and amounts to arbitrary deprivation of liberty.” (para. 13)

These challenging assertions follow from the Committee's position that Article 12 of the Convention entails that all persons, regardless of their decision-making capabilities, must enjoy “legal capacity” on an “equal basis with others”. Legal capacity involves the right to be recognized as a person before the law, as well as the right to legal agency, that is, to have one's decisions – for example, concerning health or social care, where and how to live, finances – legally recognized. “Legal capacity” is considered fundamental to personhood, equal human dignity, and full citizenship<sup>4,5</sup>.

The Committee's interpretation<sup>2</sup> states that “legal capacity” and “mental capacity” are distinct: the former is a legal concept, the latter a psychological one. Contrary to the virtually universal provisions in mental health law and capacity-based law, the Committee maintains that the existence of a disability (based on a physical, mental, sensory or psychosocial impairment) must never be grounds for denying legal capacity and the imposition of “substitute decision-making” – that is, a

decision made by another person in the place of the person with a disability (not appointed by the person, done against his or her will, and not based on his or her own “will and preferences”).

The Committee insists that the preservation of “legal capacity” means that we “must respect the rights, will and preferences of persons with disabilities”. With the appropriate support (strictly speaking for the exercise of “legal capacity”, and that the State is obligated to provide), people with disabilities will be able to express their “will and preferences”. Where a person has difficulty in communicating this directly, the Committee states that one should achieve a “best interpretation” of the person’s “will and preferences”, involving those who know the person.

Article 14 of the CRPD states that “the existence of a disability shall in no case justify a deprivation of liberty”<sup>1</sup>. On the Committee’s interpretation<sup>2</sup>, even where there is a risk to the person or to others in association with a disability, involuntary measures are nevertheless in breach of the Convention. Thus, conventional mental health law, based on a diagnosis of some form of “mental disorder” plus risk to self or others, is clearly ruled out.

This interpretation of Article 12 (together with that of Article 13 - Access to justice) has also important implications for forensic practice, including a possible prohibition of the “mental condition” defenses – “unfitness to stand trial” and “not guilty by reason of insanity” – on the grounds that defenses must be “disability-neutral”<sup>6-9</sup>.

An important background factor in the emphasis on legal capacity in the CRPD is the widespread abuse of the rights of persons with disabilities. In many places this has amounted to a loss of nearly all civil rights, sometimes termed a “civil death”.

## WHY IS THE CONVENTION IMPORTANT?

The Convention, adopted in 2006, came into force in 2008. Although it does not create rights not already existing in universal human rights treaties, it specifies how the principles of human dignity,

equality, non-discrimination, autonomy and full social participation and inclusion apply in the case of persons with disabilities. It aims to ensure that such persons are treated on an equal basis with others.

The Convention can be regarded as representing a “paradigm shift” in the legal concept of “disability”<sup>10,11</sup>. Persons with disabilities are characterized as “including those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”. This is not an exhaustive definition. Most authorities (but not all service users) accept that persons with a mental disorder treated within the mental health system are included. The Convention puts forward a “social model” of disability: it is the level of accommodations made by a society that determines the degree to which a person’s impairment becomes a disability. It is in this sense that “supported decision-making” may be necessary for a person with a mental health disability to facilitate the person’s expression of his or her “will and preferences”.

At the time of this writing, 177 States have ratified the Convention. Ratification signals the willingness of a State to foster the specified legal rights and obligations. Depending on the jurisdiction, the Convention may or may not be automatically incorporated into national law upon ratification. In many common law countries (like the UK), it is incorporated into national law only when directly legislated.

## OTHER UN INTERPRETATIONS

The UN currently has ten “treaty-based” bodies set up to monitor specific human rights legal instruments such as the CRPD. There is also the UN “charter-based” Human Rights Council, with its various “special procedures”, such as reports by “special rapporteurs”, “independent experts”, and working groups. A “flat” overall structure means that there may be significant differences in the interpretation of similar issues across these essentially independent bodies.

The CRPD Committee’s absolute prohibition on involuntary detention and treatment is supported by the Special Rapporteur on Disability<sup>12</sup>, the first Special Rapporteur on the Rights of Persons with Disabilities<sup>13</sup>, the UN Working Group on Arbitrary Detention<sup>14</sup>, and the UN High Commissioner on Human Rights<sup>15</sup>.

However, there are statements from other UN bodies that do not support the Committee’s interpretation, at least in its absolutist form.

Some positions are clearly at variance. In 2014, the Human Rights Committee published a General Comment (No. 35) on Article 9 of the International Covenant on Civil and Political Rights, which states<sup>16</sup>:

“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.”

A similar position has been taken by the Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment<sup>17</sup>.

Other UN bodies’ positions are less explicit about an absolute prohibition on involuntary interventions, but are framed in terms that support a central role for “will and preferences”. They call for an urgent need to develop alternatives to coercive interventions.

An important Resolution on Mental Health and Human Rights from the UN Human Rights Council<sup>18</sup> calls upon States to “abandon all practices that fail to respect the rights, will and preferences of all persons, on an equal basis” and to “provide mental health services for persons with mental health conditions or psychosocial disabilities on the same basis as to

those without disabilities, including on the basis of free and informed consent”.

A report of the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health<sup>19</sup> notes the lack of consensus on compulsion within the UN bodies. The Rapporteur offers to work with others to achieve one. He notes that discrimination is still evident in mental health services, for example, in depriving users of the rights to refuse treatment, to legal capacity and to privacy, as well as other civil and political rights. He insists that action is required to radically reduce coercion and to facilitate a move towards an eventual end to all forced psychiatric treatment.

A report from the UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment<sup>20</sup> seems ambiguous on whether involuntary measures can ever be justified.

Worth noting at this point is a recent decision by the European Court of Human Rights<sup>21</sup> which, whilst addressing Article 12 of the CRPD, concluded that it was justified not to accede to the expressed “preference” of a man with an intellectual disability concerning where he should live, since “the disability was of a kind that, in terms of its effects on the applicant’s cognitive skills, rendered the applicant unable to adequately understand the significance and the implications of the specific decision he wished to take”, and that, therefore, “the applicant’s well-being and interests require that the mentor [in effect, a substitute decision-maker] arrangement be maintained”. Thus, the Court’s interpretation of Article 12 did not concur with that of the CRPD Committee.

## **CRITICISMS OF THE CRPD COMMITTEE’S INTERPRETATION OF ARTICLE 12**

It is no surprise that the absolutist position of the CRPD Committee, so dramatically at odds with centuries of legal acceptance of involuntary detention and treatment, should receive harsh criticism.

An international group of clinicians<sup>22</sup> argues that the Committee’s interpreta-

tion threatens to undermine hard-won, critical rights of people with mental health disabilities – the right to the highest attainable standard of health, to life, or access to justice. Furthermore, they fear that the rights of others, the family and the public, are similarly threatened, with a consequent increase in mental illness stigma. A central necessary role for a person’s decision-making capacity is described (though, of course, in the majority of jurisdictions, capacity plays no formal role in civil commitment regimes). The authors bemoan the Committee’s apparent limited expertise in relation to mental illness, the lack of clinician input, and the Committee’s failure to consider the views of a broad population of service users, a significant proportion of whom support involuntary treatment, at least as a last resort.

Dawson<sup>23</sup>, from a legal perspective, criticizes the Committee’s interpretation for failing to offer adequate guidance on how, when situations arise where rights articulated in the CRPD are in conflict, this can be resolved. This is especially important since the relevant text of the CRPD, he maintains, is ambiguous. A key concept in many legal systems, in settling the balance between competing imperatives, is a functional test of decision-making capacity. This points to whether – in a particular instance – autonomy, on the one hand, or protection of the interests of a vulnerable person, on the other, should prevail.

Furthermore, Dawson notes that the law in general is riddled with mental concepts, deprecated by the Committee as not objective, like intention, understanding or foresight. A denial of legal capacity in a specific domain, he argues, is not necessarily a denial of intrinsic human rights. Blind persons are not allowed to drive; the key consideration is whether the person has an impairment of the relevant functions, physical or mental, necessary to act safely in that domain. Dawson criticizes the Committee’s understanding of the meaning of “discrimination”, arguing that it is not necessarily improper to treat people differently if relevant differences exist between their situations even after adequate support has been provided and reasonable accommodations made.

Scholten and Gather<sup>24</sup> argue that the Committee’s standpoint, if accepted, would result in a number of serious adverse consequences for persons with mental health disabilities. Important would be a serious effect on “autonomy” and well-being. By “autonomy” they mean “the ability to live one’s life according to one’s own conception of the good”. They state: “When a person’s decision-making competence is substantially impaired, the person is often not in the best position to assess which treatment option will be most conducive to her well-being and consistent with her conception of the good. In such cases, the practice of informed consent loses its point”.

They further argue that the Committee’s proposals would make it difficult to determine whether “undue influence” had been exerted by a supporter of the disabled person: “It will be more difficult for the medical staff to monitor the actions of support persons because the distinction between the interests of the patient and those of the support person becomes diffuse”. Related to this problem, they maintain, would be the formal allocation of responsibility for a decision exclusively to the person with a mental disability. Support persons are presumably to be left without any formal accountability.

All three critiques above have in common a key objection. They ask whether the role of a person’s ability to make a decision can be ignored, no matter the circumstances. If all efforts at support have failed, or if the person refuses support, but there is still an inability to understand the facts pertinent to the decision in question, or to appreciate their relevance, or to use, weigh, or reason with that information in terms of what is important to that person, to his or her beliefs and values, to his or her personal life goals or personal conception of the good, is his or her choice to be nevertheless accepted?

Decision-making ability is currently widely constructed as the crux around which justifications are sought for interfering in a person’s life in the interests of restoring that person’s ability to decide and thus his or her well-being. Or, as Dawson proposes, the basis on which we

work to resolve serious situations where rights contradict each other – for example the right to self-determination versus the right to life, or to the highest standard of health care, or to be free of violence and exploitation.

All three critiques also raise the related question of how we are to understand “advance directives”. At Time 1, a person with unquestioned decision-making ability may predict that, because of an anticipated future episode involving what that person recognizes as an impairment in that ability (Time 2), he or she will express a different, contradictory preference, which the person states is not to be regarded as what he or she truly or “autonomously” desires. If the feared episode occurs, which preference should be respected? The CRPD Committee provides no explicit guidance on this question. Is it the Time 2 preference, disavowed at Time 1, that is to be followed? If so, what is the point of such an advance directive?

Since significant criticisms of the Committee’s interpretation turn on the notion of decision-making ability, I suggest that an examination of how this concept might relate to the CRPD’s “respect for rights, will and preferences” may be fruitful. Such a discussion will have a strong bearing on two key principles underlying the CRPD: support for autonomy and the elimination of discrimination.

## DECISION-MAKING ABILITY, A DISABILITY-NEUTRAL LAW, AND DISCRIMINATION

Before the CRPD Committee had issued its interpretation, colleagues and I presented an argument that a “disability-neutral” law could be formulated that was non-discriminatory towards people with mental health disabilities<sup>25,26</sup>. Such a law would permit involuntary treatment when all attempts at support had failed in helping the person to make a decision that could be considered autonomous.

Such a law, we proposed – as do the critics discussed above – would be squarely based on decision-making ability. This is not a “blanket” inability but is specific to a particular treatment decision at a par-

ticular time. People with mental illness do not have an impairment of such an ability for most, or indeed all decisions, and for most or all of the time. If there was a significant impairment of this ability, involuntary treatment would only be justified if it were in the person’s “best interests”. We qualified the term “best interests” as “subjective” best interests – that is, one that gives paramount importance to the person’s deep beliefs and values, or what might be termed the person’s “will and preferences”.

We also suggested that decision-making ability itself might be construed in terms of a person’s beliefs and values. An assessment of the person’s decision-making ability would go beyond the more conventional, so-called “cognitive” elements, by examining the coherence of a person’s treatment decision with his or her relevant deep beliefs, values, and commitments. A similarity was noted to Bach and Kerzner’s influential account of how “will and preferences” could be assessed in the light of a person’s ability to express an intention (or will) and its coherence with a sense of a personal identity through time<sup>27,28</sup>.

Further, we argued it was essential that the law be “generic”. To avoid discrimination, it had to apply to all persons on an equal basis, no matter the cause of the impairment of their decision-making ability, whether it was a “mental” or “physical” disorder, nor whether they had a “disability” or not. Decision-making ability, we argued, is conceptually distinct from a “disability” and may occur in people with or without a disability.

Dawson and I had earlier proposed such a generic law, which we termed a “fusion law”, as a riposte to conventional mental health legislation. We argued that conventional law was unfairly discriminatory against people with a mental illness, in that their autonomy or right to self-determination was not accorded the same respect as given to all other patients in general medicine or surgery.

Some, including the CRPD Committee, criticize capacity-based law – even a generic law applicable to all – as discriminatory, because a disproportionate number of people with mental health dis-

abilities would be judged to lack decision-making capability, even if such a lack is specific to a time and decision. Certainly, this would constitute a “disproportionate effect”. However, a disproportionate effect does not automatically entail discrimination – in such cases, “indirect discrimination”. For example, a person with an intellectual disability is rarely accepted for training as a doctor. As entry qualifications do not explicitly exclude people with an intellectual disability, there is no “direct discrimination”. However, the entry criteria, usually requiring top class examination results in academic subjects, do have a disproportionate impact on people with an intellectual disability. Yet, we do not claim these criteria discriminate unfairly against people with an intellectual disability.

This is because it is accepted, certainly in international law, that a disproportionate effect does not amount to indirect discrimination provided its basis has three attributes: a) it has a legitimate aim, b) the criteria leading to the effect are objective, and c) the criteria are reasonable in the light of that aim<sup>29</sup>.

The “aim”, in the instances that interest us, should be seen in the terms of the fundamental principles of the CRPD: respect for the “inherent dignity of the person, and individual autonomy, including the freedom to make one’s own choices”. The aim is essentially to ensure that people experiencing a serious difficulty in making an important decision are supported in acting autonomously (according to their deeply held personal beliefs and values, their personal conception of the “good”, or “will and preferences”), and that those values are given effect through facilitation from others until the person’s autonomy is restored.

A substantial body of research on the standard criteria for “decision-making capacity” – as defined, for example, in the work of Grisso and Appelbaum<sup>30</sup> – show a level of agreement between independent assessors, a strong index of “objectivity”, that is very high<sup>31</sup>.

“Reasonableness” turns on whether the basis of the differential treatment advances the legitimate aim. Is it a reasonable and proportionate means to achieve

that aim? A person's "autonomy" – in the sense above – is necessarily related to some kind of decision-making ability. If a person is unable to make a decision reflecting or furthering his or her conception of the good, despite all measures of support, this poses an obstacle to acting autonomously.

Under what circumstances might a person have difficulties in making a treatment decision that is coherent with his or her individual conception of the good, or his or her deep beliefs and values? What the CRPD Committee has not directly considered is a common situation for people with a serious mental illness, such as a psychosis: that is, a significant, often dramatic, change in the person's preferences. Indeed, the same may occur in people without a mental illness, for example, with an organic brain syndrome caused by a brain injury or adverse drug reaction.

An examination of the terms "will and preferences" can perhaps help to clarify the elements entering into such situations; and how we might respond to them in a manner arguably consistent with the CRPD, yet sometimes allowing for an "involuntary" intervention.

### **THE MEANING OF "WILL AND PREFERENCES": "WILL" VERSUS "PREFERENCE"**

According to the CRPD Article 12, Clause 4, "States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body."

There appears to be ambiguity in this text, born of compromise. Some authorities have interpreted this clause as permitting substitute decision-making, but only

with the safeguards stated<sup>11</sup>. However, as we have seen, the CRPD Committee maintains that the exercise of legal capacity prohibits substitute decision-making and insists that we must at all times "respect the rights, will and preferences" of persons with disabilities (as we presumably do for everyone else)<sup>2</sup>. The expression "will and preferences", as noted earlier, appears in many UN bodies' statements, even in those that do not explicitly prohibit substitute decision-making.

Though the expression "will and preferences" is frequently repeated, no authority has provided a definition of its meaning. I have not found one in the "travaux préparatoires". Why were these two words, "will" and "preference", chosen? "Preference" has a relatively straightforward meaning: the Oxford English Dictionary defines it as "a greater liking for one alternative over another". On the other hand, the meaning of "will" moves us into a much more difficult territory.

In ordinary language, "will" has a stronger sense of force or resolve to act in a particular way than does a "preference". Furthermore, the "will" has a long history in the philosophy of mind. It is no surprise that the views expressed by philosophers concerning its meaning reveal significant differences. Indeed, in a recent volume dealing with the subject, the author describes the "incomplete demise" of the "modern theory of the will" that held sway from Descartes to the 19th century and came under fierce attack in the 20th century<sup>32</sup>.

A 17th century account might see the "will" as occupying a kind of causal role between the desire and the act aimed at fulfilling the desire. A distinction between the "will" and a desire (or wish or "preference") is generally drawn in the philosophical literature. Influential has been Kant's concept of the "will", helpfully summarized as: "The will, then, as distinct from the ability to choose, is the capacity to transform felt urges or desires with causal force into motivating reasons for action with justifying validity. To possess a will is therefore also to be able to test desires to see whether or not they can be validated as reasons"<sup>33</sup>. Kant's "will" forms part of a larger account including

the choice of "ends", but this is not relevant for our purposes.

Pertinent to this discussion, and shared with a number of recent accounts, is the idea of the "will" as a kind of higher-order motivating structure that determines which desires are to be translated into acts. It may be seen as having a special "reason-giving force"<sup>34</sup>, or as a higher-order self-governing mechanism, one in which "values" play a key role and where desires are subject to forms of deliberation within higher-order "policies" extending over time and expressing commitments towards ends that embody values<sup>35</sup>.

Consistent with this framework, we can develop an account of "will" and "preference" that proves helpful in understanding when we may become concerned that a person's decision-making is undermined<sup>36</sup>. A distinction may be drawn between the "will" – as a higher-order, self-governing function – as opposed to desires or inclinations or "preferences", expressed in the present. The "will", on this view, is a manifestation of a person's deeply held, reasonably stable and coherent personal beliefs, values, commitments and conception of the good. It is what we may understand as characterizing personal "autonomy". In this sense, it is not the same as a desire, inclination, or a currently held "preference", even a strongly expressed one.

Normally, "will" and "preferences", by and large, run together. It is when the "will" and a "preference" diverge or are contradictory, and a person needs to make a serious decision, that a problem may arise.

### **WHERE A "PREFERENCE" IS INCONSISTENT WITH THE "WILL": ALL PREFERENCES ARE NOT CREATED EQUAL**

For an instructive model we can return to "advance directives", cited as problematic in the critiques of the CRPD Committee's interpretation of Article 12. Noting the difference between the "will" of the person (and its associated preferences) at Time 1, as against the "preferences" that the person anticipates will be expressed at

Time 2 – and which the person asks to be ignored – it is explained why we generally respect the person's Time 1 "will" and not the Time 2 "preference". If the person were to "will" at Time 1 that treatment on an involuntary basis in the face of a predicted persistent refusal at Time 2 (as a last resort, all attempts at support having failed), the argument is strong that the Time 2 refusal should be overridden. We favor the Time 1 instruction as it reflects the person's "will" – his or her relatively stable, deeply held beliefs and values, and personal conception of the good.

To honor the preference at Time 2 is to undermine the "will" or, in essence, the "autonomy" of the person. It is hard to see how this would be consistent with the first "General Principle" of the CRPD: "Respect for [the] inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons".

If this analysis is accepted, it would follow that we would act similarly if the person had not made a written advance directive, but had expressed, through various statements and life choices, the same values (or "will") and associated "preferences", as evidenced by people who know the person well, for example, relatives and friends. Even if the person had not previously expressed clear treatment wishes, his or her previously manifest "will", as evident from his or her value commitments, life choices and goals, would have to count heavily in deciding whether or not to respect a present "preference".

Consistent with the spirit of the CRPD would be – despite an involuntary intervention – the necessity of developing a relationship aimed at facilitating the person's expression of his or her will as soon as possible<sup>27</sup>.

This analysis of "will and preferences" adds a further dimension in the conceptualization of "decision-making capacity" and "best interests", if not a major reformulation. Treatment decision-making capacity is undermined when there is a serious divergence between the person's "will" and a currently expressed treatment "preference"; while a person's "best interests" are served by acting so as to

give effect to the person's "will". An advance directive offers the clearest model. The case for an involuntary intervention is stronger, the greater the threat to the person's "will" that would result from the person enacting a contradicting "preference".

How well are we able to determine what are a person's deep beliefs, values or personal conception of the good? The tool we use is called, by philosophers, "interpretation"<sup>37-39</sup>, not to be confused with the psychoanalytic version. Interpretation involves a form of "folk" or "common-sense" psychology we use to understand and predict others' behaviour in everyday terms of mental states such as beliefs and desires. Dennett<sup>40</sup> characterized this ability as follows: "For all of its blemishes, warts and perplexities, folk psychology is an extraordinarily powerful source of prediction. It is not just prodigiously powerful but remarkably easy for human beings to use. We are virtuoso exploiters of not so much a theory as a craft". When employed collaboratively with the patient, and with people who know the patient well, one would expect an appropriate degree of "objectivity" in the assessment.

No doubt the reader will have seen some potential difficulties in this "will and preferences" approach. Here, I point to some briefly.

Can a person's "will" (and associated preferences) change without it being a sign of that "will" being undermined? Although there are accounts of a sudden, "quantum" change in a person's deep beliefs and values, these appear to be rare<sup>41</sup>. They are usually in the nature of spiritual revelations, and the result of the change appears to be an overall largely coherent conception of the "good", often of a religious nature. More commonly, a change in the "will" is gradual and understandable, usually involving a working through of value conflicts: "coherence" in an interpretive sense is maintained. Another instance where a new "will" may be seen as "authentic" may occur in a person with a long-standing psychosis, where the person has changed significantly, but where there is a sufficient degree of stability and coherence in the person's new beliefs, values,

and conception of the good, with a reasonable correspondence with the real world.

Should one always privilege the "will" over a conflicting "preference"? When the impairment of decision-making is due to a reversible cause, it is usually straightforwardly so. However, when irreversible, for example in dementia, it is arguable that the person now is not the "same person" having the previous "will". Whether that "will" should be respected rather than a strongly held but divergent "preference" in the present, I suggest, should be determined on a case-by-case basis, involving those with a close interest in the well-being of the person<sup>39</sup>.

There are situations where it may be impossible to know what a person's "will" might be – for example, a person who is unconscious or is in an organic confusional state where no-one is available who knows the person; or a person with a severe intellectual disability who may not have been able to clearly express a coherent "will" (though there may be fragments of observed behaviour and utterances pointing to what has been important to the person that offer an indication). In such cases, it has been proposed that the default position might be to consider the human rights relevant to the situation as the guide for the decision to be made<sup>42</sup>.

## **RESPECT FOR "RIGHTS" AS WELL AS "WILL" AND "PREFERENCES"?**

Just as "will" and "preferences" may point in different directions, so may "will" and "rights". When a "right" should override a clearly formulated "will" constitutes a predicament more familiar to us, usually framed as "protection" versus "autonomy".

An example is whether a right to enjoy freedom from exploitation should override a person's "will" to live alone in a situation where such a right is threatened. Its resolution might depend on a "best interpretation" of whether the person's "will" to live independently – as judged on the basis of his or her beliefs, values and conception of the good – would be consistent with accepting the level of risk to which the person would be exposed (af-

ter appropriate support services were provided).

From the previous discussion, it will be evident that the word “respect” in the phrase “one must respect the rights, will and preferences” of the person cannot mean that one must comply or accede to all those three elements. If they point in different directions, that is logically impossible.

## CONCLUSIONS

The UN CRPD is an important legal instrument clearly specifying the rights of persons with disabilities. If given effect by ratifying States, it will dramatically transform the standing in society of such persons. This is to be strongly welcome.

However, the CRPD Committee’s interpretation of Article 12 prohibiting “substitute decision-making”, while supported in some quarters, has not been fully endorsed in statements from some other UN bodies, and has drawn strong criticism from legal and clinical scholars.

An absolute prohibition on involuntary treatment is, at least at present, not credible. Nevertheless, States parties are constantly reminded of the Committee’s position in its Concluding Observations, published following regular examinations of each State’s progress in implementing the Convention<sup>43</sup>. Almost invariably, States are asked to replace regimes of “substitute decision-making” with regimes of “supported decision-making”.

While it is probable that service innovations aiming to reduce coercive measures can substantially reduce their frequency, there will always be cases – for example, due to organic confusional states or neurodegenerative disorders – where ethically persuasive justifications can be made for such measures, at the very least in circumstances carrying grave consequences. Furthermore, surveys reveal that a significant proportion of people who have been involuntarily treated for a mental illness state that such a measure can be appropriate as a last resort<sup>44-46</sup>. This indicates that law reform must involve those most directly

affected and take into account the diversity of views in this group<sup>47</sup>.

It would be an unhappy state of affairs if regard for the CRPD were undermined by the Committee’s interpretation. It should be noted that, while this interpretation is “authoritative”, it is nevertheless not “legally binding” in international law<sup>29</sup>.

Despite these concerns, the Committee’s role in drawing attention to involuntary detention and treatment is welcome. Sadly, this has been a neglected area in mental health care. We prefer not to linger on what can be a profoundly distressing and humiliating experience for patients (and a disturbing one for clinicians). The discrimination against people with a mental illness in conventional mental health law is being increasingly recognized, raising fundamental questions about justifications for compulsion.

The Committee’s objective to eliminate the obvious discrimination against persons with mental health disabilities and to pay special or paramount regard to such persons’ deeply held beliefs and values (or personal conception of the good, or “will” and “preferences”) is to be highly commended. However, by failing to analyze the meaning of the regularly endorsed phrase “respect for will and preferences”, especially in cases where there is a radical change in a person’s “preferences”, the Committee’s interpretation is incomplete.

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## Mental health and human rights in the 21st century

Mental health is emerging from the shadows. Human rights are on the agenda, and advocates are increasingly calling for parity with general health funding and a reduction of the treatment gap for people in crisis, particularly in low- and middle-income countries. There is high-level agreement on key components of good mental health policy, from promotion to prevention, treatment and rehabilitation.

However, important disagreements remain about how to invest resources. An impasse has emerged, and it risks hardening into a dispute. The controversy relates to complex connections between mental health and human rights, and coalesces around a single question: do involuntary psychiatric interventions violate international human rights law?

Coercion in psychiatry and broader mental health services is rising worldwide. This fact demands not merely discussion but action. The Convention on the Rights of Persons with Disabilities (CRPD) offers a chance for all stakeholders to rethink conventional wisdoms, address long-standing power imbalances and implement innovative practices.

Anxieties about the change must not obstruct dialog or political action. The CRPD provides a unique opportunity to liberate not just users of mental health services but the entire field of mental health from a legacy of stigma, hopelessness and discrimination. The directive of the CRPD to embrace a social or “human rights” model of disability and move away from a “medical model” of disability has strategic advantages, including shining a light on the many social, political and economic factors that create grave disparities for people with mental health conditions or psychosocial disability.

It may be tempting to focus on the most exceptional cases, which seem unmanageable without coercion. More important, however, is the need to substantially reduce coercion by implementing alternative, human rights compliant ways of providing support. Psychiatry can and must be among the leaders in this direction, not just among those resisting change.

Human rights violations in the mental health context remain significant throughout the world, including in high-, middle- and low-income countries. The prevalence of rights abuse cannot be explained by a mere lack of resources. In the relatively wealthy European region, for example, funds continue to be invested in the renovation and expansion of large scale residential and psychiatric institutions<sup>1,2</sup>. These sites perpetuate a vicious cycle of exclusion and despair. The rise elsewhere of involuntary psychiatric intervention in hospitals and homes also suggests that something is wrong.

We recognize the serious arguments of professionals who warn against a prohibition of forced treatment. They insist on retaining legal permission to treat individuals with serious mental health conditions involuntarily in exceptional circumstances in ways that preserve dignity and autonomy, even the right to life. Those against argue that the non-consensual imposition of mind- and body-altering drugs based on narrow conceptions of impairment, poorly evidenced claims about “risk” and “necessity”, and a limited range of alternatives, is incompatible with dignity and autonomy.

Scholars in diverse fields, including philosophy, neuroscience, psychology and economics, are increasingly challenging the grounds for the “exceptions” that legitimize coercion in mental health care. The CRPD has elevated this challenge to the level of international human rights law. Indeed, the CRPD challenges centuries of legally sanctioned prejudice. However, “exceptions” remain at the domestic level, in law, policy and practice, and they filter into the norm, fostering power asymmetries, the overuse of biomedical interventions, and the disempowerment of an already marginalized population. Systemic violations follow. This *status quo*, which can be observed on a global scale, is no longer acceptable.

For psychiatrists and all healing professions, a pivot toward human rights would require setting aside “substitute decision-making” and offering support

according to a person’s “will and preferences”, and where unknown, the “best interpretation” of her/his will, preferences and rights.

Szmukler’s paper<sup>3</sup> makes a substantial contribution to this effort. He elucidates some of the practical and conceptual requirements involved in a move toward a “will and preferences framework” and asks seriously what the CRPD means for the future of psychiatry, and for global health governance more generally.

One of his claims, however, raises some concerns: namely, the proposal to assess decision-making inability in the form of functional assessments of mental capacity when a person’s will and preferences are unclear or appear to be in conflict.

On this point, caution is warranted. Szmukler mentions the many critics of functional assessments of mental capacity, to whom the authors of the World Health Organization’s QualityRights Framework<sup>4</sup> could be added. Yet, his efforts to assure against discrimination or a replication of long-standing power imbalances will fail to convince many (including ourselves). He is right, however, insofar as emergency responses are needed and the dialog must continue to find grounds for intervening in ways that are just.

This Forum in *World Psychiatry*, and the WHO QualityRights Framework, are exemplary of this ongoing search. Creative responses are needed that foster therapeutic relationships based on trust and empowerment, in ways that avoid the pitfalls of the past. Moving in this direction opens space and creates urgency to develop innovative practices, some of which emerge organically when involuntary interventions are suspended or greatly restricted (as appears to have occurred in Germany, for example)<sup>5</sup>.

Academic psychiatry – as Szmukler’s own work makes eminently clear – will be essential to this shift. Clinical researchers can continue this effort by calling for the reinvestment of the vast resources currently spent on narrow biomedical research, shifting funds instead to social, clinical and community studies within

a humanistic frame<sup>6</sup>. Ties between psychiatry, public health and social sciences need to be strengthened.

There are no simple solutions. Debates may be uncomfortable, but they could open new opportunities and roles for psychiatry. The shift would diminish the “formal power” currently afforded to psychiatrists. Yet, there could be multiple benefits in shifting the profession from a tutelary to a facilitative role, including unlocking funds currently used for coercion and addressing important issues of image and reputation. It should be in the interests of psychiatry as a medical profession to substantially reduce its reliance on coercion, and to spread such a message to its members worldwide.

A rights-based approach can provide a pathway to the future of mental health care we want for all. The CRPD can be used to promote the investment of human and financial resources into a broad spectrum of support to drastically reduce non-consensual measures with a view to their elimination. It offers a framework to achieve social justice, attain the highest standard of health care, and strengthen governance of health and social services.

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## Practical strategies to end coercive practices in mental health services

Mental health has become a global imperative. Increasing coverage of treatment options and support services is crucial. However, without deep reflection and change in paradigm about the types of services being provided, we risk reproducing some of the poor outcomes and dissatisfaction that we see in high-income countries, stemming from overmedicalization, overuse and inappropriate use of medications (and their negative impacts, for example, in terms of metabolic disturbance, sexual dysfunction, premature mortality) and human rights violations associated with involuntary admission, forced treatment, seclusion and restraint<sup>1-3</sup>.

Promoting human rights in mental health *must* go hand-in-hand with efforts to scale-up services in countries, and mental health strategies and interventions must be firmly grounded in a human rights approach<sup>4</sup>.

The Convention on the Rights of Persons with Disabilities (CRPD) sets out key obligations on countries to end practices based on force, coercion and substitute decision making in mental health, and instead requires that practices be based on people's will and preferences or on

the best interpretation of their will and preferences<sup>5,6</sup>.

Coercive practices are particularly challenging to change, since they are commonly accepted in society, seen as necessary to protect persons from harm, and are firmly cemented and sanctioned in law and policy across all countries. This despite the absence of evidence for their effectiveness, and the available evidence demonstrating that practices such as seclusion and restraint actively cause harm to physical and mental health, and can lead to death<sup>7</sup>.

G. Szmukler<sup>8</sup> argues that there are exceptions where, in the interest of promoting people's autonomy, it becomes necessary to utilize involuntary interventions, and that a person's ability to make a decision should be a decisive factor in determining whether forced admission and treatment is a legitimate response. Below, we set out our disagreement with this position and also address some specific points raised by the author.

First, denying a person who is blind the right to drive is not the same as denying a person, whose decision making capacity is impaired, the right to decide on his/her admission and treatment. A person

who is blind is objectively so, and cannot drive a car. On the other hand, determining that a person's decision making is impaired is subjective. Furthermore, there is no objective way that a health or other professional can know what is best for the person, because preferences are themselves subjective. The professional does not have the same history, experience or knowledge as the person concerned about what he/she finds helpful in his/her recovery.

The underlying issue in the scenario outlined by Szmukler is not the denial of the right to drive, but rather understanding that the function of driving is first and foremost the possibility to get from A to B. A person who is blind will be primarily interested in the freedom of movement that driving affords, rather than the act of driving itself. Thus, while the act of driving may not be a guaranteed right, creating the necessary accommodations to enable him/her to get from A to B, on an equal basis with others, is an obligation under international human rights law.

Similarly, in the case of someone whose decision making is affected, the obligation is to support him/her to make his/her own decisions on an equal basis with

others. This support may mean helping the person to access relevant information, understand and weigh up the benefits and negative effects of treatment, and support him/her to assert and communicate his/her decisions and choices.

If a person is unable to communicate his/her decisions directly, these should be based on the best interpretation of his/her will and preferences. Best interpretation can be determined, for example, by drawing upon a trusted support person or network to help interpret what the person would want in the current situation, based on what is already known about him/her (e.g., his/her views, beliefs, values in life)<sup>9</sup>.

Alternatively, one can refer to a person's advance directive, containing information about his/her will and preferences should he/she be unable to communicate decisions sometime in the future. However, there are cases in which a person, who expressed a particular wish at Time 1, expresses a contrary will and preference at a later time. In such scenarios, Szmukler questions which preference should be respected. In fact, advance directives can include an "Ulysses clause", which enables people to state that any objections they may express "in the moment" should be overruled in favor of the written directive. This also allows options for people using services who report that they are in favor of involuntary treatment. However, even with a Ulysses clause, it is important to consult a support network to validate the final decision where discrepancies have arisen.

In situations where there are no support persons or advance directive available (or when an advance directive is not clear), sufficient time should be allowed for a person to make his/her decision in a safe, non-coercive environment. If there is no life threatening urgency to the situation, then decisions can be deferred to such a time that the person is able to express his/her will and preference. And even if there is urgency, one is still obliged to interpret what the person's will and preference might be, based on information that one has at hand.

In these situations it is possible that errors are made, and that decisions based

on the best interpretation turn out not to be in line with a person's will and preferences. In these situations it is essential that the experience serves as a learning opportunity to gain a deeper understanding of the person's wishes, how best to support him/her moving forward, and to prevent such incidents from re-occurring. In the aftermath of such situations, it is useful to encourage the person to develop or update advance directives and to help him/her to identify trusted persons/networks to support him/her by interpreting his/her will and preferences in the future if necessary.

In addition to achieve long-term sustainable change, policy and law will need to reflect the practice changes described above. Many recently formulated laws around mental health contain substantial provisions about "managing" the "exceptional" use of involuntary admission and treatment, as well as seclusion and restraint. However, the system of exceptions has not worked even when there have been stringent rules and restrictions about their use. Furthermore, the endless debate about what is "exceptional" has served to hinder progress and productive dialogue both at national and international levels. Energies should instead be concentrated on looking at a way forward and at strategies and solutions to promote the right of people to receive quality care and support in line with the CRPD.

Change will be required at multiple levels, including knowledge, attitudes and practices of professionals, families and others towards supporting people in their decision making, providing services that operate without force, that promote rights, recovery, and people centered care and support, and redefining policy and law so that these move beyond a narrowly focused biomedical approach in order to fully embrace a human rights approach that addresses the social determinants of mental health, and emphasizes support instead of coercion.

WHO QualityRights has developed training and guidance tools to enable national stakeholders to integrate CRPD rights into their practices<sup>10</sup>. The initiative is also developing best practice guidance identifying and providing the evidence

for community based services that operate without coercion, respond to people's needs, support recovery, and promote autonomy and inclusion. The initiative is also at the early stages of discussing new guidance for human rights oriented policy and law in line with the CRPD.

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The authors are staff members of the WHO. They alone are responsible for the views expressed in this commentary and they do not necessarily represent the decisions, policy or views of the WHO.

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# The UN Committee's interpretation of "will and preferences" can violate human rights

In the controversies with the United Nations (UN) Committee for the implementation of the Convention on the Rights of Persons with Disability (CRPD), G. Sz mukler<sup>1</sup> highlights an important point in focusing on what the manifold cited notion of a person's "will and preferences" actually means.

He sets forth that the "will" should be considered as "some kind of higher-order motivating structure that determines which desires are to be translated into acts", reflecting the person's "deeply held beliefs", while "preferences" should be considered as more superficial, momentary wishes which can undergo rapid change, e.g. by mental illness. Correspondingly, the "will" as stated in an advance directive should be overriding later expressed "preferences", because otherwise advance directives would not make sense.

I am not really convinced that this interpretation adds "a further dimension in the conceptualization of decision-making capacity and best interests", as he states. I doubt that "will" and "preferences" can be differentiated without using either psychiatric or normative concepts, both of which would be rejected from the Committee's radical perspective as discriminatory.

I have tried to reconcile psychiatric ethics with the UN CRPD<sup>2</sup>. However, I think that to find a common ground with the Committee's radical interpretation is not possible, since the clinical and legal consequences are irreconcilable.

Let us consider two clinical examples. The first is the case of a patient with delusional depression and a strong suicidal intention; the second the case of a patient with severe anorexia nervosa and a life-threatening body mass index. The first patient wants to commit suicide because he is deeply convinced to be the devil himself and to be able to save the world only by his death. The other patient has demonstrated over years that her highest value seems to be eating as little as possible, even at the price of her death.

How can we affirm that these wishes are only "preferences" and not the patients' "real" will? Either by pointing out that we know a significant number of people with similar conditions who had changed their intentions completely after psychiatric treatment, maybe with some initial coercion, and continued to live for decades even without treatment and without any intention to die. This is the "mental illness" concept. If one denies this concept and wants to deter these people from dying nonetheless, he has to suppose that their "real" will is to live, sharing the wishes of most people – living in good mental and physical health, under good conditions and with good relations to the people next to them. In other words, it means to enjoy their human rights. However, this is normative and very closely related to the "best interest" concept.

According to the Committee's position, both the above concepts are misleading. The Committee invokes a new legislation which for these two patients would result in the consequence of death. This would certainly violate some of their most important human rights: the right to life (UN CRPD, para. 10), and the right of health (UN CRPD, para. 25).

Similar to ethical principles, human rights are individually not absolute, but their degree of fulfillment is subject to their compatibility with other human rights. A typical example is circumcision of new-born boys, inducing a conflict between (the parents') freedom of religion and (the baby's) right to physical integrity. Similar deliberations are necessary in our cases. For example, in cases of patients with psychotic disorders who can live in the community with medication but end up in a seclusion room or a forensic hospital without medication, it seems shortsighted to focus only on para. 12 of the UN CRPD (equal recognition before the law), without taking into account para. 19 (living independently and being included in the community), which is likewise important for such extremely vulnerable people.

In my country (Germany), we do not have common law but a constitution, with the Federal Constitutional Court (FCC) as the highest and widely respected institution. This has the advantage that a renowned legal authority is available that is competent to clarify controversial legal issues as last instance. In 2011, the FCC published two seminal decisions on the issue of involuntary treatment<sup>3</sup>. According to the FCC, treatment with use of coercion is only admissible under very restrictive conditions. However, the FCC pointed out that, in case of lack of capacity, involuntary treatment can be even required to protect the patient's right to freedom. In this context, the FCC made clear distinctions between the "free will" (corresponding to "will" in Sz mukler's paper) and the "natural will" (corresponding to "preference" in Sz mukler's paper).

Moreover, the FCC dealt in detail with the question whether the concept of involuntary treatment is in accordance with the UN CRPD, and confirmed that it is. In addition, the FCC made in 2017 a decision in the case of a woman with breast cancer and a psychotic disorder who had refused the necessary operation because she denied being ill. Since involuntary treatment was only legal in combination with involuntary detention in a psychiatric hospital, her decision to stay voluntarily entailed that she could not be treated, and she consequently died. Retrospectively, the FCC decided that the state had a "duty to protect" in such cases and required the law to be changed, allowing treatment against a patient's will also in general hospitals. This is a careful deliberation of conflicting human rights and is completely in line with medical ethics<sup>2</sup>.

Human rights belong to the most universal and precious ideas of mankind. If the UN CRPD Committee says they are unique advocates of the human rights perspective and all of us psychiatric professionals together with our domestic laws should, at least morally, stand in the dock because of torture, this is not only

an “incomplete” view, as Szmukler says, but it is shocking and unacceptable.

We should dare to express that. Exaggerations may be sometimes necessary to achieve political goals, but exaggerations in morality and medicine can have deadly consequences. Nonetheless, the UN

CRPD itself, as Szmukler emphasized, is highly welcome, and deserves high efforts to be realized in a reasonable manner.

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## The CRPD Article 12, the limits of reductionist approaches to complex issues and the necessary search for compromise

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD)<sup>1</sup> was received with high expectations by all those concerned with the protection of the human rights of people with mental disorders and psychosocial disabilities. For most sectors of the mental health community, it appeared to be a unique opportunity to take a leap forward in the development of laws promoting the rights of this group of people and facilitating the development of community-based and human rights-oriented mental health care.

Is it possible that the UN Committee's General Comment No. 1 on Article 12 of the Convention<sup>2</sup> has created a situation in which all these expectations are in danger? Unfortunately, the danger is real. A large number of States Parties that have ratified the Convention have also expressed their disagreement with the Committee's interpretation, in particular regarding the absolute prohibition of substitute decision-making. An increasing number of human rights experts, scholars and clinicians have stated their conviction that this interpretation, if accepted, would result in serious adverse consequences for people with mental health disorders and psychosocial disabilities, and would undermine some of the hard-won critical rights of these people<sup>3</sup>. Although many mental health service users' organizations support the prohibition of involuntary admission and treatment, there are indicators showing that this view is not shared by all people with mental disorders nor by the majority of family members. In this context, we have to conclude that the possibility that gov-

ernments will change their mental health laws in accordance with the directives of the Committee seems rather remote.

How did we get into this situation? The limited involvement of some relevant sectors (e.g., clinicians) in the drafting of the Committee's Comment, and an insufficient debate about the implications and the implementation of the CRPD, were important factors. However, in my opinion, the ambiguity of the text of clause 4 of Article 12, pointed out by Szmukler<sup>4</sup>, has certainly had a very strong influence in this process. It was this ambiguity, in which it is difficult not to see an imperfect compromise between conflicting approaches, that the Committee has tried to overcome, alas, at the cost of a radical and reductionist interpretation, that is not compatible with the complexity of the issue at stake.

According to the Committee's interpretation, any form of substitute decision-making is considered a violation of the Convention's guarantee of legal capacity on an equal basis. This means that, faced with a person with a mental disorder who does not accept a treatment considered indispensable and has a severe lack of decision-making skills, a psychiatrist would not be allowed to resort to involuntary treatment in any circumstance. Because, in order to preserve legal capacity, it is necessary to respect the person's rights, will and preferences, in such a situation the psychiatrist would have to rely solely on the support that the State is obliged to provide for the person to become able to express his/her will and preferences.

This approach suffers from several fragilities and contradictions. One of these

has to do with the arguments used by the Committee to justify why the lack of decision-making skills cannot be the basis for any form of substitute decision. In fact, one of these arguments – that the assessment of these skills would be impossible – is not confirmed by the available evidence<sup>5</sup>, while the other – that its determination would be discriminatory – has been refuted by several experts, who have argued that the assessment of decision-making capacity does not need to be discriminatory in nature and can be applied to all people equally<sup>4,6</sup>.

Another example is the idea according to which, with the appropriate support, most persons with disabilities will be able to express their will and preferences, a presumption which ignores the fact that, in many situations, it is not possible to guarantee this support, while in many other situations this support will not be effective. Finally, denying persons with severe mental disorders the treatment they need, in cases where it has been proved that they lack the ability to make decisions regarding their treatment needs, and doing so in the name of “the freedom to take risks”, is, in my opinion, highly debatable from the ethical point of view.

Despite all the objections that may be leveled against the Committee's Comment, we should not forget, as Szmukler<sup>4</sup> rightly underlines, that the publication of this Comment has had several important merits. It has stimulated a debate, although this has been manifestly insufficient so far. It has called attention to the fact that, for many people with mental disorders and psychosocial disabilities,

involuntary admission and treatment may be a very painful and traumatic experience. Finally, it has represented a strong challenge to be met by the development of new contributions that may help to build a much-needed consensus.

The proposal of Szmukler and Dawson<sup>4,7</sup> goes in that direction and proves that it is possible to formulate a law that is generic, non-discriminatory towards people with mental health disabilities, based on decision-making ability in relation to a particular treatment decision at a particular time, and that permits involuntary treatment when all attempts at support have failed in helping the person to make a decision that could be considered autonomous.

The proposal of a more subjective approach to both the concept of best interests and the assessment of the person's decision-making ability could also help to ensure that the deep beliefs and values (in other words, the will and preferences) of the person are taken into consideration<sup>4</sup>. Although differing from this approach in several specific aspects, the proposals put forward by Freeman et al<sup>3</sup>

and Scholten and Gather<sup>8</sup> share some of its principles.

Important differences remain between these proposals and the Committee's view. However, they all represent valuable contributions to the construction of a formulation that will take into account the complexity of what is at stake and will have real chances of being incorporated into the mental health laws of most countries.

For this to happen, several things are necessary: a) to promote all forms of debate that may help to build a new consensus; b) to ensure the participation in the discussion of a much broader range of stakeholders (e.g., different groups of people with mental disabilities, family members, mental health professionals with clinical experience, and experts in mental health legislation and policy); c) to clarify the definition of and the relations between relevant concepts (e.g., mental disorders, disabilities, psychosocial disabilities); d) to admit that, rather than concentrating our efforts on "an absolute prohibition on involuntary treatment (that) is, at least at present, not credible"<sup>4</sup>,

we should "devote more time to thinking about how to make the essential practice of substitute decision-making as respectful as possible"<sup>9</sup>; and e) to invest more on the reform of services and practices, without which no meaningful change in protection of the human rights of people with mental disorders will ever occur.

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## The UN Convention on the Rights of Persons with Disabilities: great opportunities and dangerous interpretations

G. Szmukler's paper<sup>1</sup> provides an in-depth analysis of some critical aspects of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) that make its implementation problematic in mental health care laws and provisions.

Out of 177 States Parties that ratified the Convention, only 92 signed the Optional Protocol, and several of them expressed reservations on the Convention or explicitly put forward their interpretation of some articles<sup>2</sup>.

Actually, as correctly pointed out in Szmukler's paper<sup>1</sup>, the most critical aspects do not stem directly from the text of the Convention, but from the interpretations provided by the UN Committee set up to monitor the implementation of the Convention (CRPD Committee)<sup>3</sup>.

Articles 12 and 14 represent the best examples. The text of these articles requires appropriate measures by States Parties to guarantee persons with disabilities the support they may require in exercising their legal capacity. However, in the interpretation provided by the Committee, these articles would preclude all non-consensual treatment and substitute decision making on behalf of persons with mental disorders.

Szmukler focuses on three concepts likely to underlie misinterpretations of several articles of the Convention and generate problems in its implementation in mental health laws: legal capacity, will and preferences.

The position taken by the Committee on the issue of legal capacity is a challenge for common sense. It is based on

the assumption that mental capacity and legal capacity are independent from each other, though both of them (in particular, legal capacity in terms of legal agency) involve decision making processes. As a result, a person may lack the capability of making decisions, but will be considered able to do so from a legal point of view, in order to avoid discrimination and denial of human rights.

This assumption entails multiple risks for multiple entities. The recognition of full legal capacity would deprive the person with mental disorder of any right to benefit from the acknowledgement of a mental condition as a source of defense. In the absence of decisional capacity, a person with a severe mental disorder (e.g., psychotic disorder or dementia) may be unable to protect her/his own in-

terests, and may be victim of exploitation by others. Those who care for people with mental disorders know that this happens and, unfortunately, it is not a rare event.

It is also worth reminding all of us that several people are willing to take their own life when deeply depressed. However, when recovered from depression, the same people are very thankful to doctors who treated them (even under a coercive treatment regimen) for being still alive.

Of course, the need to support people in being actively involved in decisions relevant to their treatments, housing or finances is not questioned, and efforts aimed at identifying and disseminating the best relevant practices should be encouraged. Indeed, the shift from a classical welfare approach to one focusing on autonomy and full inclusion in the society of people with disabilities is more than welcome, as demonstrated by the ratification of the Convention by so many States Parties.

However, a rigid approach, as the one advocated by the Committee's General Comment No. 1 on Article 12, would not provide any safeguard in case support fails to enable the person's active and informed participation in the decisional process, and would leave room for exploitation and extreme irreversible decisions. As highlighted in Szmukler's paper, rigid interpretations of the Convention may result in a paradoxical situation in which both the person with mental disability and her/his unofficial carers may experience more disadvantages than advantages.

The reliance on will and preferences of the person in ensuring the exercise of legal capacity suggests a lack of clinical expertise and input in the writing of the Convention. In several neurological, psychiatric and internal medicine conditions, such as those involving quantitative and

qualitative alterations of consciousness, the possibility to assess the person's will and preferences "coherent with a sense of personal identity"<sup>1</sup> is very limited. During a manic episode, for instance, a person may prefer to behave in ways that, outside that episode, would make her/him deeply ashamed, or concerned, or even guilty. When recovered, the person might ask those around her/him why no one did anything to prevent her/him from causing so many troubles. When acutely delusional, a person might wish to donate all her/his goods to someone else, and later on, when no more delusional, feel desperate for having ruined her/himself and the whole family. Conflicts between different wills in different moments, and even among different rights, are clearly present here: in these cases, should, as noted by Szmukler, the right to enjoy freedom from exploitation override the right to act according to one's own current preferences?

In spite of the drawbacks underlined by Szmukler, advance directives might be an important resource. However, an in-depth discussion among all stakeholders is needed in order to identify the best relevant procedures and validate them in different cultural contexts.

In the light of the potentially harmful consequences of rigid interpretations, it is not surprising that several States Parties, while ratifying the UN Convention, expressed reservations on some of its articles (in particular on Articles 12, 14 and 19) and did not sign the Optional Protocol. It is also not surprising that, as highlighted by Szmukler, other UN bodies do not support the interpretations provided by the CPRD Committee<sup>4</sup>. The issue of mental disabilities is very complex, and requires high ethical standards, appropriate training, as well as mental health care services

with adequate structural and human resources.

In spite of the critical aspects highlighted in Szmukler's paper, the Convention has fueled a lively debate on inappropriately neglected hot topics which, at odds with the tendency to shortcuts and oversimplifications characteristic of the CPRD Committee and Special Rapporteur's report, seem to require accurate testing of different models and a neutral evaluation of their outcomes.

For the time being, a general agreement could and should be reached on the following aspects: a) the determination of incapacity should never be based upon diagnosis alone, as no mental disorder impairs the capability of making decisions by definition; b) in each State Party, procedures for advance directives should be identified and included in mental health laws after adequate validation; c) a careful documentation of attempts made to establish a therapeutic alliance and to support the patient in the process of making decisions relevant to her/his treatment, housing, finances, etc., should be provided in patients' clinical records.

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## Will and preferences in the overall CPRD project

G. Szmukler's paper<sup>1</sup> needs to be understood in the context of the Convention on the Rights of Persons with Disabilities (CPRD) as a whole, and what the CPRD endeavors to achieve.

The motivation for the CPRD was an acknowledgement that existing legal and policy approaches, both at the international and the national levels, were not delivering human rights for people with

disabilities<sup>2</sup>. As that relates to people with mental disabilities, that is unlikely to be contested by the readers of this journal. We are all aware of institutional systems in which people with mental disabili-

ities may spend most of their lives in conditions that are frankly deplorable. Countries of the global North sometimes portray themselves as somehow above this, but a perusal of the reports of the European Committee for the Prevention of Torture suggests that none of us has much to crow about<sup>3</sup>.

Life in the community is often not much better. Poverty is endemic, no doubt in part reflecting the risible employment rates of people with mental disabilities. Community housing is often substandard. There is little evidence of meaningful social integration, but certainly evidence of being the victims of violence, exploitation and abuse<sup>4</sup>. These problems are international: we all have to own them as they relate to our own countries, wherever we are.

In that sense, the CRPD is an attempt to hit the reset button. It tries to create a fresh start in international human rights law, envisaging a world where people with disabilities do get to enjoy the rights and the meaningful lives that the rest of us take for granted<sup>2</sup>. When commentators speak of the CRPD introducing a “new paradigm”, that is what is meant: it is an acknowledgement that the way we have approached human rights of people with disabilities since the Second World War (and perhaps for centuries before) needs a fundamental rethink.

Fundamental to that is a challenge to rethink the role of the state, and its relationship to people with disabilities. Traditionally, the role of the state has been one of control. Mental disabilities provide a particularly clear example of this: we have locked up people with mental disabilities because of perceived dangerousness, or “for their own good”, or to remove them from the public gaze, or to allow their family carers to work. When we have established community programmes for them, social workers and similar professionals have been expected to keep a close eye on their lives. Usually this has been done with good intentions; but it has created a second class citizenship, where rights are contingent in a way not experienced by the rest of society.

The CRPD is not anti-state or libertarian. Instead, it re-casts the state, not as a manager of people with disabilities, but in a support role. If people with disabilities are to enjoy the meaningful lives the rest of us expect, supports have to be put in place to bring this about, and that requires either service provision by states, or services provided under state regulation. The services do need to be what people with disabilities want, however: these people should not be required as a matter of state policy to take what is on offer, any more than any other citizen should. The CRPD envisages a world where people with disabilities get to make the same choices as the rest of us.

Szmukler is correct that a number of international human rights bodies have been slow to pick this up, but that is appropriately a criticism of those bodies. It is difficult to see how the existing human rights systems that those bodies perpetuate can provide the legal, cultural, policy and ideological shifts that are required to make human rights real for people with disabilities. The failure of these existing systems for people with disabilities was, after all, the reason why the CRPD was perceived as needed, and the international human rights bodies noted by Szmukler need to own that truth.

That is not necessarily to say that the position of the CRPD Committee is to be taken uncritically or as unassailable. It is to say that the problems the CRPD is intended to address are real, and critics of the CRPD position should be challenged to provide positive alternatives, rather than to trot out the approaches of the past that have proven insufficient.

What does all this mean for Szmukler's analysis? Three points are of particular relevance.

The first is that in Szmukler's analysis, as elsewhere in the literature, the debates about capacity, supported vs. best interests decision-making, and the CRPD Committee's General Comment No. 1<sup>5</sup> take place in isolation from the bigger pictures of what needs to change for people with disabilities. Unsurprisingly, physicians view these issues through the lens of medicine and the effects on their prac-

tice. Almost certainly, this will only be a small piece of what is required.

Further, decision-making is only relevant if there are options to choose between. The changes needed to realize the CRPD ambition will no doubt include provision of the best available standards of health, but provisions for example concerning the structures of social care and benefits, housing, and community integration will also be pivotal. We should all be working with people with disabilities to articulate those broader changes in ways relevant to our own countries. The discussion of how decisions should be taken in “hard cases” needs to occur in that broader set of contexts, not just within clinical treatment.

The second issue is how far Szmukler's analysis actually diverges from the CRPD Committee's approach in General Comment No. 1. He does seem to suggest that the influence of the will and preferences of a person with disability in determining a decision should be directly proportional to the clarity and reliability of those will and preferences. That already seems to be moving a considerable distance from the hard capacity/incapacity divide of current law.

Szmukler might well be agreeable to proper support being offered to the person with disability in reaching and articulating views. While he does not use the phrase, his view would appear to be that, in hard cases, decisions should be taken based on the “best approximation” of the person's will and preferences – the CRPD Committee's approach. There is admittedly some divergence on what constitute hard cases, but the similarity of Szmukler's position to that of the Committee is notable. Certainly, versions of Szmukler's approach could mean a considerable move from the managerial ethos of the current system – and that is very much consistent with the CRPD.

Finally, there is the question of who should support the person with disability in articulating his/her will and preferences, and deciding what weight should be given to divergent views expressed by the person. Psychiatrists, like many other care professionals, have for generations

been at the centre of the culture that people with disabilities are to be managed by the state – the old paradigm. If a will and preferences approach is to be provided by psychiatrists in a non-managerial way, and if psychiatrists are to have the trust of people with disabilities in providing the support in articulating will and preferences, psychiatry will have to break from

the old, controlling paradigm. It is not clear whether psychiatry as a profession is ready to make that break.

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## The rejection of capacity assessments in favor of respect for will and preferences: the radical promise of the UN Convention on the Rights of Persons with Disabilities

G. Szmukler<sup>1</sup> argues for an interpretation of “will and preferences” that allows for determinations of decision-making ability, in the form of functional assessments of mental capacity, to be used to interpret the decisions of those who appear to display conflicting will and preferences.

In this commentary, I will focus on three core issues which arise from Szmukler's approach: the issue of indirect discrimination in functional assessments of mental capacity, the dilemma of advance decisions, and the need for a human rights compliant response in a situation where the individual's preference(s) appears to conflict with his/her will.

Concerning the first issue, Szmukler argues that the application of functional assessments of decision-making ability should not be regarded as unlawful discrimination, because these serve a legitimate aim, the assessments are objective in nature, and meet the criteria of reasonableness and proportionality in pursuit of their legitimate aim.

Even if the notion of a legitimate aim – protecting the totality of the person's human rights – is accepted, it is far less certain whether functional assessments of capacity can be considered objective in nature, or a reasonable and proportionate response to resolving a perceived conflict of rights. Szmukler cites Grisso and Appelbaum's review of measures used to assess competence<sup>2</sup> in support of the argument for objectivity, but this is by no means an uncontested position in the literature.

For example, Morgan and Veitch<sup>3</sup> criticize the purported objectivity of mental capacity assessments. They argue that “the real point of legal tests for mental capacity seems not to be to assess some projected future or, indeed, past ability to make a choice... but to assess whether the person making that decision can construct a convincing case why he or she reaches the standard of the ‘ability’ that law expects in such circumstances”.

In support of this argument, Haidt<sup>4</sup> and Iyengar and Lepper<sup>5</sup> showed that individuals only conjure up reasons for their decisions when called upon to do so, and these reasons rarely correlate with their actual decision-making process at the time of the original decision, but rather reflect the most persuasive explanation the person can find for his/her decision.

These studies suggest that the process of assessing an individual's mental capacity, even on a functional basis, is an inherently subjective and value-laden one. Therefore, the use of such assessments to restrict or deny legal capacity violates the requirement of objectivity demanded by human rights norms in order to avoid the categorization of disability-based discrimination.

It is also clear that the use of functional assessments of mental capacity to reconcile perceived conflicts of rights, will and preferences does not meet the criteria of reasonableness and proportionality. With increasing evidence of the effectiveness of alternatives to substitute decision-

making<sup>6</sup>, a reliance on mental capacity assessments as a trigger for (potentially coercive) interventions seems less and less reasonable. As long as alternative, less intrusive measures exist which could be used to reconcile perceived conflicting will and preferences, it cannot be proportionate to impose substitute decision-making based on an external decision-maker's functional assessment of an individual's mental capacity to make a particular decision.

The second issue I wish to address relates to advance directives. Such directives – which are listed in the Committee on the Rights of Persons with Disabilities' General Comment No. 1<sup>7</sup> as an important example of support to exercise legal capacity – can easily be reframed away from the capacity/incapacity paradigm, to give the directive-maker much greater flexibility to determine when the directive becomes operational. In other words, the perceived absence of functional mental capacity should not be the automatic legal trigger for a directive entering into force. Instead, the directive-maker should specify the circumstances in which he/she wishes his/her directive to take effect.

A directive-maker could, for example, specify that the directive should be activated once he/she starts exhibiting certain behaviors, or when he/she is admitted to hospital, or when a number of trusted supporters named in the directive all agree that he/she is now in crisis or unable to communicate. This ensures that the power remains with the directive-maker

to set the conditions under which the directive will take legal effect.

As for the thorny question of Ulysses clauses, in my view it should be possible for individuals to include these in directives if they so choose. In practice, I anticipate that the use of such clauses would be very rare, as most people will not want to bind their future selves to a situation that they would not then be able to reverse. But, as this is an important support option which some individuals wish to have, it should be available to persons with disabilities on an equal basis with others.

The final issue I wish to address is how a human rights compliant response can be developed where we perceive an individual's will and preferences to be in conflict and incapable of reconciliation. As I have previously argued<sup>8</sup>, where will and preferences conflict, a number of strategies can be employed. First of all, what an outsider might perceive as a conflict between will and preferences may not be perceived by the individual decision-maker as problematic – it might reflect a change of approach from past decisions based on experience, a new perspective, or simply the fact that the person has changed his/her mind.

A human rights compliant approach to resolving these perceived conflicts involves engaging in all forms of commu-

nication with the person, and speaking with those the person indicates are trusted supporters to inform the interpretation of his/her will and preferences in this specific situation. It may happen during this process that the will and preferences of the person become clear. If the will and preferences of the person remain unclear following all efforts, and a decision still needs to be made, the interpreter will have to make a decision informed by the “best interpretation” of the person's will and preferences he/she arrives at, given all the information available about the person's wishes.

Others have suggested that a “best interpretation” means “the interpretation of an adult's behaviour and/or communication that seems most reasonably justified in the circumstances”, and that “decision-making supporters must be able to provide a reasonable account of how this interpretation was arrived at”<sup>9</sup>.

The process of arriving at a “best interpretation” of will and preferences is inevitably challenging and fraught with uncertainty, but, if the new paradigm heralded by the Convention on the Rights of Persons with Disability (CRPD) is to mean anything, it must be understood that this process is radically different from how determinations of decision-making ability have been undertaken in the past.

Therefore, contrary to what Szmukler proposes, it is my contention – in keeping with the jurisprudence of the CRPD Committee – that functional assessments of mental capacity cannot be used to determine whether a particular preference should take precedence over what others perceive to be the individual's will, or whether third parties' interpretation of a person's will can justify ignoring the individual's clearly expressed preference.

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## The UN Convention: a service user perspective

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD)<sup>1</sup> has sparked quite a global debate around Articles 12 (Equal recognition before the law) and 14 (Liberty and security of the person), and their relation to involuntary hospitalization and treatment.

In light of this controversy, the South African Federation for Mental Health (SAFMH) has conducted an engagement exercise with mental health care users who had experienced involuntary hospitalization. Seventy-one percent of participants indicated that they were in favor of involuntary treatment, and specified that their preference was due to acknowledg-

ing that there had been intervals during a relapse where they were unable to act in their own best interest.

The participants felt that the practice of involuntary treatment “protected” them from their own behaviour at a time of relapse where they may not have control over their actions, and which may consequently result in personal harm or harm to others (harm not specifically defined as physical harm but including psychological harm).

Participants, however, emphasized that they had more often not been involved in decision-making when it came to treatment options. They noted that their expe-

riences with involuntary hospitalization had happened without consultation, and that they became aware of what was going on only when the ambulance and/or police arrived. They further noted that involuntary hospitalization would in most instances not have been necessary should they have been consulted and would have agreed to voluntarily go to hospital for treatment.

Paternalism has a long history in psychiatry<sup>2</sup>, sometimes with the best of intentions, but it is a disempowering component of the mental health care system, where others instinctively tend to take on a decision-making role. Paternalism

