## 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 onethird 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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