Will and preferences in the overall CRPD project

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G. Szmukler's paper[1] needs to be understood in the context of the Convention on the Rights of Persons with Disabilities (CRPD) as a whole, and what the CRPD endeavours to achieve.

The motivation for the CRPD 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[2]. 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 disabilities 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[3].

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[4]. 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[2]. 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 1[5] 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 practice. 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 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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1 Szmukler G. World Psychiatry 2019;18: .
2 MacKay D. Syracuse J Int'l L & Com 2006-7;34:323-31.
3 European Committee for the Prevention of Torture. https://www.coe.int/en/web/cpt/states.
4 Bartlett P, Schulze M. Int J Law Psychiatry 2017;53:2-14.
5 Committee on the Rights of Persons with Disabilities. General Comment No. 1 on Article 12: Equal recognition before the law. CRPD/C/GC/1. 2014.