

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

denies the opportunity to make an informed decision through a consultative process (or through a supported decision-making process when necessary) to allow for the will and preferences of mental health care users to be acknowledged, respected and executed.

Assumptions are often made instinctively as to the decision-making capacity of a mental health care user, without any determination on whether the person is in fact unable/able to make an informed decision or needs support to make a decision. Moreover, paternalistic decision-making may reinforce self-stigma and lead to poorer health outcomes<sup>3</sup>.

Mental health care systems need to take bold steps and strategically redesign the way in which services are provided, to ensure alignment with international human rights standards and evidence-based interventions, with an emphasis on empowerment, recovery and mental health care user involvement in the evaluation of the system. An example of a mental health care system that achieved considerable transformation is the “Open Door – No Restraint” system in Italy<sup>4</sup>, focusing on recovery and citizenship, where mental health care users are at the centre of service delivery.

Apart from reverting away from abruptly dismissing the will and preferences of service users when it comes to treatment options, the change should pay serious attention to the environment in which services are delivered. Psychiatric facilities often look and function more like prisons than places of care and recovery. The dilapidated state of such facilities impacts on bioethical principles that should promote respect for autonomy, non-maleficence, beneficence, and justice.

Psychiatric facilities and mental health services have been noted as environments in which human rights violations are most likely to take place<sup>5</sup>, and where service users’ voices are often silenced. It is, therefore, a logical expectation that a person will refuse admission to such psychiatric facilities if the environment which should help and care for him/her exposes him/her to degrading and undignified treatment, adding to the psychological dis-

stress that he/she may experience at the time.

In South Africa, persons refusing hospital treatment may be resistant not because of diminished legal or mental capacity (however perceived), but because of the knowledge of what happens in those facilities.

In the engagement exercise conducted by SAFMH, the word “dignity” came up several times where participants explained how the mental health care system had violated their rights. Words describing their experiences included “devastated”, “frightened”, “confused”, “undignified”, “violated”, “criminalized”, “treated as less than human”, “Nazi concentration camp”, “tied down like a dog”.

My own experience of involuntary hospitalization was more traumatic than the devastating symptoms I experienced with my diagnosed schizophrenia. I refused voluntary hospitalization based on past experience of uncondusive and abusive conditions within the hospital. Even though my will and preference was aimed at obtaining treatment, just not in such an environment, yet I was considered to have diminished decision-making capacity and to be unable to acknowledge what was in my own best interest.

On the other hand, the CRPD Committee’s interpretation of the Convention’s Articles 12 and 13, which would mean that the “insanity plea” would be scrapped as far as “unfitness to stand trial” and “not guilty by reason of insanity” are concerned, may have consequences that impact on a person with a mental disorder who enters the justice system. A case study in South Africa that I have dealt with in my advocacy work gives insight into this.

A person with a diagnosis of schizophrenia who in a psychotic state caused damage to property, in response to voices that instructed him to do so, was arrested and stood trial without his diagnosis at any point being introduced as a defense. Consequently, he was found guilty and served a prison sentence. Upon release, he failed to obtain employment merely because of his criminal record. In the alternative scenario where he could have

been found “not guilty by reason of insanity”, he would not have had a criminal record that now prevents him from obtaining employment and ultimately independence. The question is: was it a fair trial if the circumstances surrounding his actions on the day of the damage to property were not considered?

Prison systems may often not be equipped or sufficiently resourced to care for and protect people with mental disorders from victimization and abuse, or may not be able to provide an adequate standard of mental health care and services to this population. Even in a more resourced country like the US, prisoners with mental disorders are “more likely than other prisoners to be held in solitary confinement, be financially exploited, physically and sexually assaulted, commit suicide, or be intentionally self-destructive”<sup>6</sup>.

Any person, whether he/she has a mental disorder, a disability or not, may at some point be unable to make an informed decision (for whatever reason) and, where will and preference are in contradiction, there must be a mechanism that protects the individual.

To avoid stigmatization and discrimination, I support Szmukler’s suggestion<sup>7</sup> of a law that is solely based on decision-making ability, with a clear definition of will and preference, human rights and best interest processes to be considered on an individual case basis, opposed to a law that is specifically aimed at persons with mental disorders.

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