

The right to health

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to have a [whole] life

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1966 International Covenant on Economic, Social and Cultural Rights [ICESCR]

the right to health:

‘the right to the enjoyment of the highest
attainable standard of health without
discrimination’

The CRPD and healthcare

CRPD, article 25 reiterates the classic formulation of the right to health as set out in the ICESCR

However, CRPD focus not on health and healthcare

CRPD based on a number of principles including the principles of autonomy and free choice, equality, respect for difference and non-discrimination, participation, inclusion and accessibility (CRPD, article 3)

This is not to suggest that health and healthcare have no importance in achieving these general principles.

On the contrary, the CRPD requires an adjustment of these principles and the approach of medical law and ethics in order to do justice to the human rights of people with disabilities in the healthcare sector

Different from medical ethics and, to a lesser extent, medical law, the CRPD is not so much focused on regulating the performance of medical professionals, but rather on guaranteeing that people with disabilities, irrespective of the cause, nature or severity of their impairments, and no matter their needs for medical care, actually get the healthcare they need and want

The CRPD thus
also emphasizes
the importance of autonomy
in cases where disabilities
may impair the capacity of individuals
to make healthcare decisions.

Article 25 of the CRPD

- = the longest and most programmatic explanation of the right to health of any of the human rights treaties
- sets out the obligation of States to ‘take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation’

CRPD established priorities, ensuring that people with disabilities get 'the same range, quality and standard of free or affordable healthcare and programmes as provided to other persons' (CRPD, article 25(a))

INCLUDING access to sexual and reproductive healthcare and public health programmes

States need to provide healthcare to alleviate, insofar as is possible, someone's disability.

Early identification and intervention, and 'services designed to minimize and prevent further disabilities, including among children and older persons' are among the actions which fall under this mandate (CRPD, article 25(b)).

- CRPD emphasizes the provision of healthcare ‘as close as possible to people's own communities, including in rural areas’ (CRPD, article 25(c))
- Articles 25(d) to (f) of the CRPD then set out overarching principles, reiterating the principles contained in article 3:
 - >>> **they require the State to ensure** that its medical professionals provide equal quality care, which is given ‘on the basis of free and informed consent

Equal quality should be achieved

by pursuing actions that may include raising awareness of human rights 'through training and the promulgation of ethical standards' for medical professionals (CRPD, article 25(c)).

- The CRPD recognizes health in parallel with the broader notion of independence, a concept that implies autonomy and the obligation to provide support to exercise autonomy
- Health can play an important part in reversing the invisibility of people with disabilities
- Healthcare systems are unable to do this alone as many determinants of health are not within the realm of control of healthcare (income and other socio-economic determinants ie housing have, on a population basis, a greater effect on health than the quality of healthcare)

- The right to adequate housing is set out in article 28 of the CRPD on social protection, and appears alongside other essentials of health, such as water, food, clothing, social protection, poverty alleviation and so on.
- Housing does not mean simply having a roof over one's head, but is framed in terms of access to, and participation in the community
- Central to this right is the obligation of States to provide a range of 'in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community' (CRPD, article 19)

This provision speaks to the right to habilitation and rehabilitation, whereby health services should be directed towards enabling people with disabilities 'to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life' (CRPD, article 26(1))

When treatment becomes ill-treatment

Despite the normative clarity of the CRPD on the right to live in the community, some people with disabilities are forced to live in institutions, often for their entire lives, without their consent, and they are unable to challenge the underlying decision.

These institutions are often healthcare establishments such as psychiatric hospitals, or social care institutions where people are forced to take psychiatric medication

Legal and ethical dilemmas for the responsible healthcare providers

what to do when laws prescribe forms of forced treatment, ignoring the consent of the patient, while the conditions under which the patient will be treated amount to inhuman and degrading treatment ???

- Prior to the adoption of the CRPD, international law on psychiatric treatment was mainly extrapolated from other human rights treaties, such as a 1994 General Comment by the UN Committee on Economic, Social and Cultural Rights [CESCR] on disability (General Comment No. 5)
- As progressive as this General Comment was in many respects, it did not address forced psychiatric treatment

General Comment on the right to health (General Comment No. 14 2000) did not examine mental health in any depth, stating that mental health treatment without consent is allowed on an 'exceptional basis', without explaining why it is allowed at all, or explaining this exceptional bases (CESCR 2000, paragraph 34)

Both of these general comments referred to a **non-binding** document adopted in 1991 by the UN General Assembly called the 'Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Healthcare' [MI Principles]

MI Principles set 'the right to be treated in the least restrictive environment, with the least restrictive or intrusive treatment appropriate to the patient's health needs and the need to protect the physical safety of others' (principle 9(1))

no treatment shall be given to a patient without his or her informed consent' (MI Principles, principle 11)

Five exceptions to MI principle 11 including a scenario where a doctor thinks that that it is 'urgently necessary in order to prevent immediate or imminent harm to the patient or to other persons' (principle 11(8))

This watering down of normative standards led Paul Hunt, the then UN Special Rapporteur on the Right to Health, to observe in his 2005 report on disability and the right to health that ***while informed consent is necessary to provide treatment and 'is consistent with fundamental tenets of international human rights law', the combined effect of the 'extensive exceptions and qualifications' 'tends to render the right of informed consent almost meaningless'*** (UN Economic and Social Council 2005, paragraph 88)

- Reiterating that the right to health is subject to progressive realisation (CRPD, article 4(2)), Paul Hunt highlighted that ***‘the international right to health also imposes some obligations of immediate effect’*** (UN Economic and Social Council 2005, paragraph 34), ***which includes freedom from non-consensual medical treatment, or as the CRPD puts it, the obligation of States to ensure that medical professionals provide healthcare to people with disabilities on the basis of free and informed consent*** (CRPD, article 25(d)).

- Though clear on informed consent, the CRPD is silent on forced treatment.
- CRPD neither explicitly permits force when someone lacks the capacity to consent to treatment nor does it ban forced psychiatric treatment.
- CRPD does not define ‘informed consent’ nor does it offer guidance as to the actions medical professionals should take when, for whatever reason, it is not possible to seek patient consent.

- Despite this, others have stepped up to the challenge of filling the void with human rights content:
- Manfred Nowak, the (then) UN Special Rapporteur on Torture, issued a report on torture and disability in which he notes that people with disabilities are subject to treatment without their consent (UN General Assembly 2008):
- **he highlights in particular the effects of ‘electroshock treatment and mind-altering drugs including neuroleptics’ (UN General Assembly 2008, paragraph 40) >>> Nowak calls for a review of the anti-torture framework in relation to disability**

- Nowak's successor as special rapporteur, Juan Méndez goes further than Nowak in observing **how ill-treatment is justified by rhetorical devices such as 'best interests' which are masked as 'good intentions' of medical professionals** (UN General Assembly 2013)

- **Méndez advises States to revise laws** ‘that allow detention on mental health grounds or in mental health facilities and any coercive interventions or treatments in the mental health setting without the free and informed consent by the person concerned’ (UN General Assembly 2013, paragraph 89(d))

Méndez cites Anand Grover's 2009 report, **the 'Right of everyone to the enjoyment of the highest attainable standard of physical and mental health'**, which discusses various international and domestic laws that enshrine informed consent as a fundamental principle, before observing that it **is, 'frequently compromised in the health-care setting'** (UN General Assembly 2013, paragraph 29)

The CRPD Committee shares this view in its 'Draft General Comment on Article 12' (2013b). The Committee reiterates the wording of article 25 on the right to health, and points out that:

[States are obliged] to require all health and medical professionals (including psychiatric professionals) to obtain free and informed consent from persons with disabilities. In conjunction with the right to legal capacity on an equal basis with others, this also obligates States to refrain from permitting substitute decision-makers to provide consent on behalf of persons with disabilities. (2013b, paragraph 37)

- CRPD offers no guidance as to the actions medical professionals must take beyond a non-discrimination approach.
- It does, however, make a process point about how these issues are to be discussed and decided upon.
- Article 4(3) of the CRPD imposes on States a general obligation when laws and policies are developed and implemented.

- Medical ethics is traditionally centered on the principles of autonomy, beneficence, non-maleficence and justice.
- Doctors and other medical professionals ultimately decide how these principles are to be applied in individual cases.
- the human rights of people with disabilities have frequently been disregarded or devalued within the healthcare system (explained by a lack of understanding and cooperation between the human rights and healthcare domains, by discriminatory laws which result in poor practices, and by a lack of inclusion of PwD in public health and other development programmes)

- The advent of the CRPD in 2006 provides an opportunity for people occupying various domains in society, notably in the field of healthcare, to critically assess their engagement with people with disabilities

- A shift in the conceptualization of healthcare for people with disabilities through a human rights lens should be a clarion call to medical professionals, and those who teach and train medical law and ethics, to alter care practices in the name of justice, beneficence and non-maleficence

- Such a shift also requires the political will to address some very challenging dilemmas about how to move from a model of proxy consent to one which truly respects the will and preferences of the person with disabilities when accessing healthcare;

- Medical professionals must abide by their national laws. They are in a difficult position when their national law does not comply with international human rights standards
- If this is the case, medical professionals can capitalize on the power and authority of their professional organizations and liaise with patients' rights organizations about how to instigate legal reform that better meets the healthcare needs of people with disabilities – their patients.

- It is also incumbent on medical professionals to become acquainted with the current international human rights standards in depth.
- Training should feature in medical school curricula and continue post-qualification;
- This coincides with recommendations made by the CRPD Committee
- that training and legislative reforms should be done ‘in consultation and cooperation with persons with disabilities and their representative organizations, at the national, regional and local levels for all actors

Thank you !!!

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