



Reversing hard won victories in the name of human rights: a critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities

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The UN Convention on the Rights of Persons with Disabilities (CRPD) is a major milestone in safeguarding the rights of persons with disabilities. However, the General Comment on Article 12 of the CRPD threatens to undermine critical rights for persons with mental disabilities, including the enjoyment of the highest attainable standard of health, access to justice, the right to liberty, and the right to life. Stigma and discrimination might also increase. Much hinges on the Committee on the Rights of Persons with Disabilities' view that all persons have legal capacity at all times irrespective of mental status, and hence involuntary admission and treatment, substitute decision-making, and diversion from the criminal justice system are deemed indefensible. The General Comment requires urgent consideration with the full participation of practitioners and a broad range of user and family groups.

Introduction

Abuse of the human rights of persons with mental disabilities is widespread and well documented.¹ Maltreatment and neglect are particularly rampant in low-income and middle-income countries where violations often occur in the absence of protective legislation.² Stigma and dehumanisation of persons with mental illness and mental disability often make the form and extent of abuse particularly heinous.³ In this context, the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD) with its stated purpose "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity"⁴ is strongly welcomed. Although previous UN agreements set valuable precedents in protecting the human rights of all people, the UN CRPD gives explicit focus to the rights of those with disabilities, including their fundamental right to live in communities, rather than being confined in institutions, and as such is a leap forward in reaching human rights goals advanced by advocates and activists of human rights of persons with mental disabilities over many years.

It is of concern, however, that the rights so eloquently captured in the Convention, and the actions required by States that have ratified the convention, are seriously threatened by a recently released General Comment⁵ by the Committee on the Rights of Persons with Disabilities, the UN entity assigned to interpret the Convention. The General Comment dismisses prevailing concepts of mental and legal capacity, and as such, seeks to abolish all forms of substituted decision-making or guardianship, involuntary admission, and treatment under any circumstances or for any length of time, and diversion from the prison system based on mental incapacity. It is debatable whether this comment accurately captures the intention of the Convention text and the countries that

have ratified it (for example, several countries submitted reservations at the outset, including Australia, Canada, Estonia, Norway, and Poland), but what is most important is that following the publication of the General Comment, countries that originally ratified the CRPD are facing intense pressure to implement far reaching changes that challenge fundamental principles of mental health care and treatment hitherto widely accepted as reflecting a human rights perspective (for example, in the WHO Resource Book on Mental Health, Human Rights and Legislation⁶).

The impact of the Convention might indeed be paradoxical and instead of enhancing human rights, several fundamental rights, such as the enjoyment of the highest attainable standard of health, access to justice, the right to liberty, and even the right to life, might instead be violated and subject to unintended consequences. Moreover, the human rights of others, such as family members and members of the public, could also be infringed upon. Stigma and discrimination might also increase rather than decrease if some interpretations of the General Comment are accepted without modification. Different conclusions could have been reached with wider involvement of stakeholders such as clinicians, professional organisations, and a broad range of user groups.

The UN CRPD and General Comment on Article 12

The UN CRPD was adopted by the UN General Assembly in December, 2006, and entered into force in May, 2008. It was subsequently ratified or acceded to by 152 nation States. At the time of writing (January, 2015), 30 States had signed but not ratified the Convention.

In April, 2014, the Committee on the Rights of Persons with Disabilities, the UN entity assigned to monitor implementation of the Convention, finalised a General Comment concerning Article 12 (and related articles), in which prevailing concepts of mental and legal capacity

were summarily overturned. This interpretation departs from previous intergovernmental agreements on human rights and earlier WHO recommendations on mental health law.⁶ At the centre of much of the controversy is the term “legal capacity”. Article 12 Section 2 of the CRPD says “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life”.⁴ The Committee consequently asserts that henceforth substituted decision-making, compulsory treatment, involuntary admissions, and diversion from the criminal system process on the grounds of mental disability (sometimes called the insanity defence) should be abolished. The magnitude of the changes now asked of countries is enormous, yet the implications seem to have largely flown under the radar of most governments and the mental health sector.

In the introduction of the General Comment, the Committee states “...there has been a general failure to understand that the human rights-based model of disability implies a shift from the substituted decision-making paradigm to one that is based on supported decision-making”.⁵ This change in approach leads the Committee to state that State Parties have an obligation to require all health and medical professionals (including psychiatric professionals) to obtain the free and informed consent of persons with disabilities before any treatment and not to permit admission to hospital unless requested by the user.

The General Comment defines mental capacity as “the decision-making skills of a person” and rejects prevailing medical conceptions of mental capacity, stating that it is “highly controversial” and that mental capacity “is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon”.⁵ The Committee argues that mental capacity and legal capacity should not be “conflated”,⁵ and that impaired decision-making skills should not be justification for suspension of legal capacity.

We submit that the Committee’s interpretation and conclusions are highly problematic. We fully agree that disability should never be the sole reason for the suspension of a person’s rights, and also that in both the realms of health care and in court all persons should be presumed to have both mental and legal capacity. We submit though that where it is proven in a given case from thorough psychiatric assessment that the person does not have decision-making capacity in a particular domain (for example with respect to hospital admission, treatment, or financial transactions), at a particular time, that the initial legal presumption must also be reassessed. In other words, legal capacity should always be assumed unless evidence, which must include a range of principled and practical checks and balances, proves the contrary. In such cases, safeguards should be proportionate to the person’s circumstances, and to how far the measures affect the person’s rights and interests.

Additionally, such measures should apply for the shortest time possible, and should be subject to regular review by an independent or judicial body.

Informed consent

Informed consent for treatment or hospital admission is a vital ethical health-care principle, and it should not be over-ridden without stringent consideration and assessment. However, there are times when informed consent is not possible because of the condition of the person and must be superseded, particularly where life is at risk. With respect to life-saving treatment, a person in a coma or a person with severe infectious or neurological disease, for example, might need treatment without his or her informed consent. A universal presumption of legal capacity and the primacy of supported decision-making therefore cannot be absolute and exceptions have to be considered. This must apply to both physical and mental health.

In our view, excluding any exemption to the presumption of legal capacity due to mental impairment, and as a result not allowing a person with severe mental illness or other impairment to have their circumstance treated as exceptional, might in fact violate his or her rights, and in some circumstances could result in harm to self or to others.

Theorists have proposed frameworks for informed consent⁷ and several countries have legislated in this regard. For example, Applebaum has proposed a widely used clinical rubric for assessing capacity to consent to (or to refuse) treatment.⁸ He suggests that if after receiving information about his or her condition and proposed treatment, a person demonstrates capacity to consistently communicate a choice regarding treatment, demonstrates understanding of information presented by the clinician and their recommendations, acknowledges their medical illness and the likely consequences of treatment options, and is able to engage in a rational process of manipulating the relevant information, then they can be said to give informed consent. The Mental Capacity Act (2005) in England states that a person has capacity in relation to a specific issue if he or she can understand the information, state belief or insight, retain the information, weigh or use the information, and communicate the decision.⁹

Consent obtained when a person does not have such decision-making capacity is not informed and therefore not valid. Critically, the capacity to give informed consent can be hampered by many different conditions, including both physical and mental conditions. We are unclear as to whether the Committee would accept exceptions to the informed consent principle as long as the reason for the exception were not disability. Hence, we might imagine that if a person carries a diagnosis of mental illness, but independently has an infection that causes a delirium and is refusing life-saving treatment, he or she can be treated without consent only if his or

her refusal to have treatment was because of delirium and not their mental illness.

The Committee's interpretation conflates the notions of disability, a long-term state, and mental capacity, which is based on a time-limited assessment. In fact, the decision for involuntary hospital admission or treatment should not be based solely on diagnosis of disability, but rather a time-limited assessment of a person's mental state, safety, and decision-making capacity. Szmukler and colleagues¹⁰ make a case for unlinking disability and capacity in the interest of minimising discrimination. They argue that determination of decision-making capacity need not be discriminatory in nature and can be applied to all people equally, whether on the basis of a mental disorder or a physical disorder. Kontos and colleagues¹¹ instead argue that although capacity assessments can be done independent of diagnoses, this assessment might not be a good idea in that the illness underlying a mental status helps identify the course of action needed, for example psychosis from acute intoxication of a stimulant requires a different approach than does psychosis from schizophrenia.

Violation of rights

Further, the Committee's interpretation is not consistent with other values and rights expressed and asserted throughout the CRPD.

The right to enjoyment of the highest attainable standard of health

Article 25 asks States Parties to "Require health professionals to provide care of the same quality to persons with disabilities as to others". The dilemma of informed consent aside, if a person having a severe exacerbation of affective or psychotic illness is not provided proven, effective treatment, can he or she be said to be receiving the highest attainable standard of health? Best evidence so far on psychiatric disorders tells us that some severe psychotic illnesses can impair decision-making capacity. For example, the ICD-10 states that "the schizophrenic disorders are characterized in general by fundamental and characteristic distortions of thinking and perception...The most important psychopathological phenomena include thought echo; thought insertion or withdrawal; thought broadcasting; delusional perception and delusions of control; influence or passivity; hallucinatory voices commenting or discussing the patient in the third person; thought disorders and negative symptoms."¹² That is, decision-making might be by definition impaired and hence merely supporting decisions when a person is in a state of severe psychosis, including treatment decisions, could seriously undermine that person's right to health care.

Importantly, the likelihood of a person making a recovery to the point of regaining capacity and therefore

being able to give informed consent is often diminished without treatment. In the example of psychosis, we might be undermining the right to health to allow a person to stay in a psychotic state and never allow them to get to a point of refusing or accepting treatment in an informed manner. The question then becomes whether involuntary treatment of a person with psychosis can be given at least to the point at which sufficient recovery has been made to make an informed decision. Even if the "right to health" is not a sufficient justification to treat a person without consent, what if a person with mental illness is a danger to self or to others? For example, what if the person is hearing voices that tell him or her to hurt themselves or another person? Should such a person rather be left to harm himself or herself or others or to go to jail rather than be admitted to hospital without their consent? (See also Right to liberty). Despite agreeing fully with the argument that involuntary admissions and compulsory treatment are often overused, and have historically resulted in the rights of people being violated, we cannot accept that doing away completely with involuntary admission and treatment will promote the rights of persons with mental illness.

Interestingly, the Committee favours advance directives whereby a person plans in advance for a period "where they may be unable to communicate their wishes to others", yet states that a person has legal capacity at all times. Presumably, it is the wishes at a time of wellness that are being referred to and not those during an acute, severe exacerbation of mental illness. The Committee's argument is inconsistent in this instance. If all people with mental disabilities have legal capacity at all times (as the Committee suggests), there would surely be no need for advance directives.

Right to liberty

The CRPD says that "the existence of a disability shall in no case justify a deprivation of liberty". This is an important principle that deserves support, particularly as mental disability has historically been used as justification to remove people from their communities and restrict them to institutions. However, application of an absolute rule of not admitting a person because of mental disability could in some circumstances result in the long-term deprivation of liberty—possibly in a prison—rather than a potentially much short(er)-term "deprivation" in a hospital. In several countries, in addition to being mentally ill, danger to self or others is a precondition to admit a person without their consent as an added protection against arbitrary or unnecessary admission. This precondition is not valid in all countries. For example, in Italian law it is not dangerousness that is the base for an involuntary admission but the need for treatment. It is argued that since dangerousness is not a disease, dangerousness should be a police problem and is not a medical

problem. The involuntary admission is therefore based solely on the need for treatment. Yet with or without a dangerousness requirement in law, in specific circumstances of mental illness, by temporarily admitting a person without their consent, longer-term deprivation of liberty can be avoided.

Right to justice

Legal capacity means that all people, including those with disabilities, have full legal standing and legal agency simply by virtue of being human (clause 14).

The Committee's General Comment does not directly address diversion for mental health treatment from the criminal justice system. However, if a person is assumed to have legal agency and legal standing, then competency to stand trial and criminal responsibility for one's actions follow. Although the Committee did not directly comment on the so-called insanity defence, this notion would appear inconsistent with the Committee's conception of legal capacity. Statements made by the UN Special Rapporteur on Disability, Shuaib Chalklen, seem to confirm this position. In a May, 2014, letter to the Human Rights Committee, he states "In the criminal law context...involuntary transfer to mental health facilities within or outside of a prison, or the imposition of mental health treatment as a condition of probation or parole, violates CRPD Article 14 and cannot be considered a reasonable accommodation for disability."¹³

In most domestic courts, to be found guilty of a serious crime necessitates proving that one must have: (1) committed the crime, (2) intended to commit the crime, and (3) known that what one was doing was wrong at the time. These criteria are known as the M'Naghten Rules¹⁴ and, according to them, every person is presumed "sane" until proven otherwise. The related notion of mens rea or "guilty mind" is invoked in legal settings and involves various levels of "guilt." Moreover, most courts require the accused to be able to follow court proceedings in order to be tried and sentenced. Failure to do this owing to mental incapacity is usually reason to divert the accused. We argue that without mens rea as a litmus test for culpability in a crime with respect to mental state, society would effectively discriminate against persons with mental illness and persons with mental illness would be held to a higher standard than other persons.

Further problems arise if a person with mental illness is jailed rather than diverted to mental health treatment. First, treatment in prison, even if the prisoner accepted such treatment, is likely to be less effective than treatment in a hospital setting because of differences in staff expertise and environment. Second, the person might be a victim of violence due to stigma and discrimination against persons with mental disorders, and third, should the prisoner be "disruptive", the prison authorities would have little power to provide

medical assistance unless consent were given. In view of the circumstances in most prisons, psychotic behaviour might bring serious consequences—if not from the prison authorities, then from other inmates. Thus, convicting a person who committed a crime as a result of serious mental illness and sentencing them to prison rather than diverting them for treatment and possible quick discharge is unlikely to be to their benefit.

Right to life

Article 10 (right to life) asks States Parties to "reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others." Despite this affirmation, the General Comment seems to prohibit attempts to prevent suicide of a person with mental disability by family, communities, or clinicians if these attempts include admission or treatment without consent. In some cases, this limitation would close viable options for saving lives and is especially tragic where the suicidal ideation is directly linked with impaired decision-making capacity and could have been changed through admission or treatment. In the event that a life could be saved from suicide, we submit that the Committee's assertion that involuntary treatment should never be allowed is wrong.

Similarly, in rare instances others might be harmed or their lives taken in select circumstances, whereas admission or treatment of a person with mental disability might prevent this. When there is a conflict between different rights, the right to life should trump other rights.

Increasing stigma and discrimination

Discrimination adds to the disability of people with mental illness.¹⁵ Incidents in which people with mental disability are associated with violent and criminal behaviour exacerbate such stigma. One might imagine that a consequence of the General Comment's interpretation is that there might end up being more persons with severe mental illness untreated in the community, which might exacerbate ignorance, fear, and stigma surrounding mental disorders. An unintended consequence of the General Comment might be more public calls for the locking up of people with mental disabilities or human rights violations of untreated persons with severe mental illness in the community. Although the best available evidence-based intervention to reduce stigma is social contact with people with mental illness,¹⁵ contact with people with untreated, severe mental illness might well have the opposite effect.

How did we get to this state of affairs?

The question then becomes, why does the General Comment Committee's interpretation veer so sharply

away from previous intergovernmental agreements and from what is currently deemed best medical practice? The answer possibly lies in two areas, first the near-total absence of clinical experts on the Committee, and second the limited consultation with users.

At inception, no members of the Committee had a clinical or related background (medical, clinical psychology, or graduate degree in social work). After the second election, one member of the Committee had a medical degree, who served a 2-year term and was not re-elected. At present, no members of the Committee have a clinical background. It is this iteration of the Committee that finalised the General Comment.

Bartlett¹⁶ writes when discussing Article 17 that members of the medical profession were not involved in the negotiations of the draft Convention. The omission of clinician voices seems to have become a pattern in the later phases of interpreting and implementing, as noted above with respect to the composition of the Committee.

The involvement of service users in drafting the CRPD and the General Comment was prioritised and we fully agree with this principle. We acknowledge that many mental health service users and organisations advocating on their behalf feel strongly that involuntary admission and treatment should be done away with and many such organisations submitted statements to the Committee for consideration in finalising the General Comment.¹⁷

However, we suggest that service user input was not broad enough to represent a range of different service user views. In responding to a request from the South African Department of Health on whether there should be involuntary admission and treatment, the Gauteng Consumer Advocacy Movement (GCAM), a large user group, said “The GCAM is in favour of involuntary admission...We acknowledge that there are times when we as mental health care users relapse and become mentally unstable and therefore not capable of acting in our own best interest, especially when it comes to treatment and the various ways of obtaining the necessary treatment, which may include involuntary admission. We also acknowledge that at times some of us might become verbally or physically abusive or threatening, and it is then the responsibility of the State to protect those around us and protecting us from harming ourselves” (personal communication). The GCAM did a survey of their members in 2013 and found that 99% felt that “psychiatric medication has resulted in improved mental health and improved quality of life” (personal communication).

In India, Pathare and colleagues¹⁸ found that 93.3% of service user respondents acknowledged the “need to be taken to a clinic or a hospital to see a doctor during a period of decisional incapacity” and various warning signs were identified by the participants themselves including “unable to take decisions on my own”,

“hitting my family or pets”, “not interacting with anyone”, and “if I talk too much to myself”. Family members are also usually strong advocates of some form of involuntary admission and treatment and are often the people who make the applications for involuntary admission and treatment¹⁹ when they fail to convince their family member that treatment is needed.

Further, some advocacy organisations submitted statements for consideration by the Committee in finalising the General Comment that raised the question of limited uses of involuntary treatment, including the Swedish National Association for Social and Mental Health (RSMH), the Norwegian Federation of Organizations of Disabled Persons, and the Danish Institute for Human Rights. The Swedish Association wrote: “As stated in this and other contexts RSMH firmly believe that supported decision-making in general is the better option to accommodate and support the individual’s rights both under the convention and in a practical sense.....There are however, in our view, under some circumstances an unacceptable level of risk for the individual with seriously diminished mental capacity in the exercise of full agency to the point of self-harm or the right to veto necessary decisions when *periculum in mora*.”²⁰

Several States Parties also submitted statements in support of substituted decision-making in limited circumstances for consideration by the Committee in finalising the General Comment, including Norway, Germany, Denmark, and France. Norway’s statement reflected back to the interpretive declarations made by the country at the time of ratification, reserving the right to withdraw legal capacity and allow for compulsory care or treatment in limited circumstances. Speaking of their initial declarations, Norway stated: “The existence of several declarations similar to the Norwegian declarations, the state reports submitted to the Committee and recent national legislation intended to implement the Convention, indicate a general understanding among the States Parties that the Convention allows for substitute decision-making, provided that such provisions meet certain criteria and are subject to legal safeguards.”²¹

Germany reported in its statement, “It seems therefore that the Committee’s interpretation is not shared by the State Parties in general; not even by a substantial minority.”²²

Germany continued, “While sharing the view that the provision of support for persons with disabilities is the best possible way to help them exercise their rights, Germany remains convinced that there are situations in which persons with disabilities simply are not able to make decisions even with the best support available. Therefore, while representing a shift in focus from substitute decision-making to supported decision-making, the Convention could not and in Germany’s

view does not rule out the possibility of substitute decision-making in some cases”.

Conclusion

As the formal interpretation to internationally binding law, the implications of the General Comment for the UN CRPD for mental health are enormous, yet up to now neither governments nor mental health providers seem to have embraced or acted seriously on the directives. We note that Article 4 of the CRPD states that “Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of persons with disabilities and which may be contained in the law of a State Party or international law in force for that State. There shall be no restriction upon or derogation from any of the human rights and fundamental freedoms recognized or existing in any State Party to the present Convention pursuant to law, conventions, regulation or custom on the pretext that the present Convention does not recognize such rights or freedoms or that it recognizes them to a lesser extent.” It perhaps follows that where some interpretations of the CRPD in fact derogate human rights, governments will not change their laws and practices.

Yet the General Comment is very clear in what is expected from countries and already several countries are being put under pressure to make legal and practical changes to be in line with the General Comment. For example, in the Concluding Observations on Paraguay’s report,²³ the Committee writes that they are “concerned at the State party’s mechanism for declaring persons with disabilities legally incapable and regrets the lack of understanding in the State party concerning the scope of article 12 of the Convention”; and on Argentina’s report,²⁴ the Committee writes that it is “deeply concerned” that the nation’s existing and proposed legislation were based on a substituted decision-making model. The Committee wrote that it “urges the State party to launch an immediate review of all current legislation that is based on a substitute decision-making model that deprives persons with disabilities of their legal capacity”. South Africa has received similar comments.

A consensus (or near consensus) would be needed to replace existing mental health laws with new laws consistent with all the CRPD principles, and compatible with other rights, including to the highest attainable standard of health of people with severe mental disorders who might at times have impaired decision-making capacity. Action and advocacy by clinicians, practitioners, professional organisations, and a wide range of service user groups are thus urgently needed to ensure that implementation of the UN CRPD generates laws and practices that indeed safeguard the rights of persons with mental disabilities.

Contributors

MCF conceptualised the report, contributed to the literature search, collated contributions, and wrote the final draft. KK contributed to the literature search, did the research into the process of writing the UN Convention on the Rights of Persons with Disabilities, analysed country comments, and drafted parts of the Personal View. The other authors were part of the expert group that decided a Personal View was needed, contributed ideas, drafted parts of the Personal View, added points to early drafts, and assisted with the editorial.

Declaration of interests

MCF, KK, JMCdA, AK, NM, SP, and BS declare no competing interests. GT is the chair of (NGO) Human Rights in Mental Health (F-GIP).

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