

Draft General Comment on Article 12 of the Convention

Submission to the UN Committee on the Rights of Persons with Disabilities from the Cambridge Intellectual and Developmental Disabilities Research Group (www.CIDDRG.org.uk), part of the Department of Psychiatry at the University of Cambridge. We are an interdisciplinary group, comprising clinical academics and academic researchers, which seeks to use research to improve the lives of men and women with intellectual and other developmental disabilities; some of our relevant research is listed in Appendix 1.

Introduction:

We welcome the *Convention on the Rights of Persons with Disabilities* for the leadership and encouragement it provides to men, women, and children with disabilities, self-advocates, care-givers, clinicians and other practitioners, NGOs, and national governments who seek the same rights and opportunities as their non-disabled peers. This is especially so for individuals with intellectual disabilities who are so often denied even minimal services and regularly exposed to gross violations of their human rights. Whether segregated and secluded in large institutions or in community settings, people with intellectual disabilities are routinely denied the right to exercise control over their own lives. There are others too, who for different reasons, also have compromised intellectual functioning, and in the face of unhelpful societal responses, experience significant disadvantages. They also need the protections enshrined through the CRPD.

Background

We note the Committee's assertion that equality before the law - as set out in Article 12 of the *Convention on the Rights of Persons with Disabilities* (CRPD) - is to be seen as a foundational principle underpinning all human rights protections. For this reason, it is asserted, legal capacity must be treated as a universal attribute applicable to all adults everywhere, and under all circumstances. We are also aware that the Committee believes that many States Parties, misunderstanding the scope of Article 12, have sought to justify a distinction between legal capacity and mental capacity. Such a distinction, it is stated, is incompatible with a human rights approach to challenging discrimination against persons with disabilities: the argument is that perceived deficits in a person's mental capacity are used to deny legal capacity. This denial becomes the means for both restricting a person's opportunities to make decisions for herself and for imposing decisions made by others (substitute decisions). It is stated that legal capacity is indispensable for the exercise of economic, social and cultural rights, so that by denying legal capacity to persons with disabilities it would only perpetuate the violation of such human rights as the right to vote, marry and found a family, as well as, for example, the right to consent prior to medical treatment, and the right to liberty. Central to the CRPD's paradigm change is therefore a shift from legal regimes that include substitute decision-making to ones of supported decision-making. The Committee asserts that irrespective of formal decision-

making skills, the will and preferences of all adults with disabilities must be respected on an equal basis with those of others. In order to achieve this, States must: (i) put in place processes for supported decision-making, including any necessary safeguards, and (ii) immediately begin replacing existing laws that permit the making of substitute decisions.

We are in full agreement with the trans-national aspirations of CRPD, and general principles of the Committee's *Draft General Comment* on Article 12. In a previous submission, we put the case against the universal attribution of legal capacity; we will not reiterate our argument. There is no easy way of reconciling the claim that universal legal capacity is required to protect the right to self-determination and autonomy with the claim that, under certain circumstances, a substitute decision, in the best interests of the relevant individual, may be needed. Claimants on both sides seek to protect the dignity and right of individuals with disabilities, and as such deserve to be taken seriously.

Concerns about the Draft General Comment

The document is hard to read: it is not only repetitive but is also, at times, contradictory. The statement that 'a mechanism for third parties to challenge a decision of a supporter if s/he believes the supporter is not acting based on the will and preference of the individual' (paragraph 25 section (d)), gives the impression that the supporter might be making a decision. Relatedly, it is uncertain whether such 'mechanisms' (i) can be effective given that supported-decision-making is a subtle and complex task, and (ii) are compatible with respect for privacy on an equal basis with others (Article 22). Moreover, the Committee needs to define the meaning of 'free and full consent' (Article 25). More fundamentally, however, the views set out in document are too blunt and lack subtlety. We believe that, as a consequence, the influence of the *Comment* may be diluted and even undermine the rights of individuals with disabilities, including their right to life, to access to healthcare, and to access to justice. The issues need to be considered further before the Committee attempts to issue a definitive *General Comment on Article 12*, and before it can reasonably expect States Parties to revise their legislation. To varying degrees, such legislation relies on a distinction between so-called 'competent' and 'incompetent' persons, or, using other terminology, between those judged to have or not to have the 'capacity' to make specific decisions for themselves. In no way do we dispute the principle of a presumption of legal capacity for adults. Not to do so and to argue that, because of the presence of some disability, someone lacks capacity would be discriminatory; it is clearly unacceptable. Moreover, we very strongly endorse the view that support to enable individuals to participate in making decisions for themselves is good practice. What we regard as highly problematic is the claim that no one would ever require someone else to make a decision on our behalf. Notwithstanding improvements in the practice of supported decision-making, as well as an increasing use of advance directives, there will be individuals, such as those who are unconscious, who are living in a persistent vegetative state, have very advanced dementia, or have the most profound intellectual disabilities, who will not be in a position to understand that there is a decision to be made, the nature of that decision, or the consequence of any apparently expressed will or preference; indeed, some of them will be unable to express any will or preference. Such men and women may be exploited, neglected, or even left to die when substitute care and treatment decisions are not made that could have prevented suffering and improved the quality of their lives.

In the following section, we set out some of the issues that we believe the *General Comment* needs to address and resolve in order to be effective in influencing States Parties. We have

drawn on some case examples from our own experience or from situations that have led to challenges in the English courts, or to public debate, to illustrate our points.

Issues for the General Comment to address

1. The assumption that different regimes for substitute decision-making are all the same is unconvincing. Plenary guardianship, based on a person's status as someone with an intellectual disability, that intrudes into all aspects of her decision-making cannot easily be compared with a statutory framework, such as that of the *Mental Capacity Act (England & Wales) 2005* (MCA), where the starting-point is the presumption of adults' capacity to make decisions for themselves. Under the MCA, substitute decisions in a person's best interests can *only* be made if that person lacks the capacity to make the specific decision for herself at that particular time and when all practicable support has already been provided to optimise her capacity. Any decision that is made on the person's behalf must involve her by attempting to ascertain her wishes, values and beliefs and ensuring that these are given due consideration in the decision-making process. Moreover, even where a substitute decision is made on behalf of the person, then she must participate in that decision as much as possible. Such an approach may not, in practice, be that different from the *Committee's* conception of supported decision-making where the person concerned has extreme difficulties in making one or more specific decisions for herself. Our purpose is not to defend the MCA and we acknowledge that its implementation has been problematic. Our point is that this is an example, and not the only example, of legislation in countries within the UN that seeks to balance empowerment and protection for individuals for whom some, or many, kinds of decisions may be problematic. This needs to be recognised in order to secure the support of States Parties for the wider goals of the *CRPD*.

2. We are concerned about the introduction of the concept of 'psycho-social disabilities', which is not defined, does not appear in the *CRPD*, and, we believe, may extend the meaning of disability so far that it loses some of its power. There is already a huge range of conditions that may affect decision-making in different ways; some of these are progressive (the dementias), some are stable but enduring or lifelong (some types of mental illness, acquired brain injury, intellectual disability), some are fluctuating (many mental health problems or illnesses), and some are temporary (infection, pain). Moreover, each of these groups contains a diverse range of individuals. Disability, far from 'evolving', as is asserted in the *Committee's* document, is highly contested, especially where biomedical and social models appear at odds. We think it would be helpful if the *General Comment* sought to acknowledge this contest and attempt some *rapprochement*.

3. Relatedly, while recognising historic abuses perpetrated by members of the medical profession it should not be overlooked that these professionals also have much to offer people with disabilities. For example, now that people with Down's Syndrome live longer, it has become clear that as they grow older, many of them develop Alzheimer's disease, leading to dementia. These men and women have a right to expect that they will receive the best possible assessment and treatment. Biomedical research not only seeks such a treatment, it has immeasurably improved our understanding of the early signs and progress of this disease. As a result people with Down's Syndrome and those who care about them can begin working together and planning for the future. We are concerned that with its polemical and one-sided approach, the *Draft General Comment* can be too easily dismissed by those in the medical profession that it seeks to influence.

4. The assumption of legal capacity in all situations may inadvertently compromise other rights for people with decision-making difficulties that are associated with, or are a reflection of, their disabilities. For example, necessary treatments may be refused (Art. 25); valuable assets signed away for a trifle (Art. 12 (5)); a court appearance may be unfair because a suspect refuses legal advice in police custody and makes very serious admissions (Article 13 (1)). In these, and many other situations, there is a possibility that the rights of the person may be denied; at the same time, others may act on her behalf, apparently according to her will and preferences. The Committee may wish to consider the following examples:

(i) A man who was previously active and happy has a long history of remitting and relapsing schizophrenia. During a period of relapse, he stops eating in the belief that food is turning to concrete in his stomach. He refuses treatment and is at risk of dying. If medical care and treatment is not permitted in the absence of 'free and full consent', how is this man's health, and indeed his life, to be preserved?

(ii) A woman with intellectual disabilities has made most of her own decisions for herself; for others, she has sought the support of her family. . She now has dementia and no longer recognises her parents for who they are. She is fearful of them and refuses their support with any kinds of decisions. Her personal care and physical health have deteriorated and she is in debt. How can she be supported in a way that maintains her self-respect and dignity as the dementia continues to progress?

(iii) A man with a complex combination of disabilities, including an autism spectrum condition, severe intellectual disabilities, and very limited communication skills is diagnosed with a form of cancer. There is a very good chance of responding to treatment but the man is known to fear medical settings. He appears to be refusing treatment. But on what is this refusal based?

There may be different views about how best to resolve such situations: some will argue that the person's will and preferences should be determinative; others that the right to life, or some other principle, trumps all other rights. Each, however, requires judgments that include the person's views, as far as they can be ascertained, and are respectful, informed, and proportionate.

Concluding remarks

We hope the Committee finds our comments useful. As we have stated, we are supportive of the *CRPD* and of the principles that it sets out that seek to eliminate discriminatory attitudes towards people with disabilities when it comes to citizenship and social inclusion; this is of the utmost importance. However, if equality before the law is to be meaningful and a general and basic principle of all other human rights protections, it must be cognisant of, and take into account, the complex realities of the lives of people whose ability to make decisions for themselves is compromised as a result of their disability. Not to do so, we believe, fails to provide *equality before the law*. The Committee will be aware that the rights of people with a mental illness and those with intellectual disabilities were protected in separate and distinct human rights instruments (Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, UN, 1991; Declaration on the Rights of Mentally Retarded Persons, UN 1971). Whilst the language and some of the principles in these documents is out-dated, these instruments did recognise the need for and permitted the making of substitute decisions. It was accepted that, under prescribed conditions, and with appropriate safeguards, regimes that allow for substitute decision-making may in fact, be indispensable if people with disabilities whose decision-making may be compromised are to lead lives in which they can both exercise, and have protected, their human rights.

A document of such international importance as the *Draft Comment* and indeed the *CPRD* must be able to command respect. We fear that this cannot be achieved by ignoring the reality of the disabilities that may compromise decision-making in relation to some, or to all, decisions. In particular circumstances, complex judgments about how to respond have to be made. The starting-point must be the presumption that *all* adults have the right to make decisions about their own lives; with that goes the acceptance of responsibility for the consequences of those decisions. There cannot be any reason to exclude a person from making decisions about herself on the grounds simply that she has a disability. However, we believe that the belief that everyone can make a decision with support risks disrespect for human rights and dignity. We would welcome a document in which the Committee articulated the tensions between consent, supported decision-making, and substitute decision-making and set out the principles that should guide States Parties.

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Appendix 1:

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