

Submission to the *Committee on the Rights of Persons with Disabilities* from the Cambridge Intellectual and Developmental Disabilities Research Group (www.cidrdr.org.uk) responding to the call for papers on:

The practical and theoretical measures for the implementation of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities

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Article 12 of the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD) guarantees both equal recognition before the law (12.1) and legal capacity (12.2):

States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

In keeping with the adoption of a social model of disability the CRPD recognises that some people with disabilities will require support if they are to exercise legal capacity. Article 12.3 requires States to, “provide access by persons with disabilities to the support they may require in exercising their legal capacity”. While Article 12.4 recognises that this kind of support is not without risks:

State parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall also be proportional to the degree to which such measures affect the person’s rights and interests.

The CRPD’s unequivocal recognition of autonomy and independence along with the right of people with disabilities to make choices effectively rules out - on grounds of a person’s diagnostic status - substitute decisions, medical treatment without consent (Article 25) and actions that might result in a deprivation of liberty (Article 14).

With respect to people with intellectual disabilities Article 12 does however raise two troubling problems: (1) ensuring that supported decision-making does not “drift” into substitute decision-making and (2) the fact that a social model of disability which

focuses exclusively on barriers to autonomy may not always function to protect the interests, or even the right to life (Article 10) of people with intellectual disabilities. These two problems are discussed below, and are followed by the points we believe should be considered by the Committee on the Rights of Persons with Disabilities.

(1) Ensuring that supported decisions do not become substitute decisions

Supported decision-making is a subtle and complex task (European Foundation Centre, 2010). This is especially so for people with intellectual disabilities who are often thought to be susceptible to the influence of others. To date there is little guidance - let alone any consensus - as to how the veracity or legal standing of a supported decision is to be established, or even how to determine that a supported decision is not a substitute decision. This is a matter for concern as the CRPD places significant emphasis on free and full consent: Article 23 with respect to marriage and founding a family, says that this has to be on the basis of the “free and full consent” of the intending spouses (23.1.a); Article 25, addressing the health rights of people with disabilities stipulates that healthcare must be provided on the basis of “free and informed consent” (25.d) and Article 15 makes a similar provision with respect to participating in medical or scientific experimentation (15.1). Despite the significance of “free and informed consent” as a marker of autonomy it is not defined in the CRPD. The absence of such a definition precludes the possibility of establishing a threshold below which it can be said that a person lacks the capacity to give consent. Furthermore, unless it can be safely established that consent was both given freely and is informed, parties (especially those in healthcare and banking where there are significant legal liabilities) may be reluctant to enter into agreements involving persons with intellectual disability.

Moreover, the absence of a definition of free and informed consent (or functional mental capacity) promulgates a view that with appropriate support all people, even those whose intellectual disability is severe or profound, can, in every area of life, exercise full legal capacity. Although this view is debatable there is still a good reason why States that subscribed to this view may wish to retain the power to authorise and regulate substitute decisions. There will be occasions where persons with an intellectual disability have no one in their lives who is sufficiently intimate and trustworthy to provide a level of support adequate to enabling a decision to be made and communicated. Under these circumstances it will necessary for States, in order to protect the interests of the persons concerned, to have the power to authorise and regulate one or more substitute decisions. In the absence of such powers States may find themselves unable to act to protect a person’s right to life (Article 10) should he or she be faced with a decision concerning, for example, life sustaining medical treatment.

2) The suitability of a social model of disability for people with intellectual disabilities

The emphasis placed on supported decision-making in the CRPD both presumes and promotes decision-making. However, the presence of an intellectual disability means that a person’s intellectual functioning, the ability to learn, reason, and problem solve is limited (see the definition of the American Association of Intellectual and Developmental Disability). By adopting a social model of disability (at the expense of bio-medical considerations) the CRPD glosses over differences between physical and intellectual disabilities, and also variations in the severity of a person’s intellectual disability. Without doubt many people with intellectual disabilities can and do benefit from decision-making support. This is not so, however, for all people

with an intellectual disability. There are people whose impairments are so intrinsically limiting that no amount of support will enable them to make some decisions autonomously. For these people the CRPD's requirement that States remove prohibitions against the exercise of legal capacity may in fact be detrimental to their interests. The erroneous presumption that a person has decision-making capacity may result in that person being supported to make decisions with little or no understanding of their consequences, a possibility that could, for example, lead to (i) ill-health or death when medical treatments are apparently refused, or (ii) economic insecurity where the implications of financial decisions are not fully understood. In order to guard against self-neglect and thus protect a person's right to life (Article 10) States need properly regulated procedures for authorising substitute decisions.

It is an inescapable fact that in the 21st century social relations are regulated both legally and culturally through contractual agreements. Decision-making capacity is a prerequisite for entering such exchanges, thus there will always be a need to make one or more decisions on behalf of some men and women whose intellectual disability is such that they lack the functional capacity to give free and informed consent. Recognising that some people with an intellectual disability will lack the capacity to make one or more decisions should not be seen as sanctioning the right of others to make decisions on behalf of *all* disabled people, or as endorsing a negative image of disability. Substitute decisions are a means of protecting the interests of that segment of the population who are vulnerable as a result of being unable to make autonomous decisions.

Points for consideration by the Committee on the Rights of Persons with Disabilities
Social barriers, be they attitudinal or environmental, undoubtedly limit the extent to which people with intellectual disabilities can enjoy their human rights and fundamental freedoms. People with intellectual disabilities can and do benefit from decision-making support, nevertheless there are circumstances where people with intellectual disabilities are limited by their impairments not simply by social barriers (Shakespeare, 2006). Circumstances such as these can only be identified where States have a functional definition of decision-making capacity. Without such a functional definition States may be unable to ensure that decision-making support is free of conflicts of interest and undue influence.

In England and Wales the *Mental Capacity Act* (MCA) adopts a functional definition of decision-making capacity, as well as providing a clear and transparent process for making substitute decisions that gives due consideration to people's will and preferences, where these can be ascertained. In its guiding principles the MCA states that:

- (2) A person must be assumed to have capacity unless it is established that he lacks capacity.
- (3) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
- (4) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

Assessing a person's decision-making capacity is a two stage processes: (1) does the person have an impairment of, or a disturbance in the functioning of, the mind or brain (s.2) and (2) is the person unable to: understand the information relevant to the

decision, retaining it and using as part of a decision-making process and then communicating a decision whether by talking, using sign language or any other means (s.3:1). Where it is judged that a person lacks the capacity to make a specific decision the MCA states that any substitute decision must be made in the person's "best interests". This is determined as follows:

- (1) In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of
 - (a) the person's age or appearance, or
 - (b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests.
- (2) The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.
- (3) He must consider—
 - (a) whether it is likely that the person will at some time have capacity in relation to the matter in question, and
 - (b) if it appears likely that he will, when that is likely to be.
- (4) He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.
- (5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.
- (6) He must consider, so far as is reasonably ascertainable—
 - (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
 - (b) the beliefs and values that would be likely to influence his decision if he had capacity, and
 - (c) the other factors that he would be likely to consider if he were able to do so.
- (7) He must take into account, if it is practicable and appropriate to consult them, the views of—
 - (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
 - (b) anyone engaged in caring for the person or interested in his welfare,

Section 1 (above) guards against discrimination; Sections 2 and 3 and 4 ensure that that person is supported to participate in the decision-making process; Section 5 protects the person's right to life; Section 6 ensures the person is supported to participate by referring to past decisions and other evidence testifying to wishes, values and beliefs. And Section 7 ensures that other people able to communicate with the person and interested in his or her welfare are also involved in the decision-

making process. These safeguards should ensure that the support people with intellectual impairments receive conforms with Article 12:4 of the CRPD by being: respectful of their individual rights, will and preferences; is free of conflict of interest and undue influence; and is proportional and tailored to their personal circumstances, as well as being subject to independent review.

The procedures adopted by the MCA also have the merit of according with the General Principles (Article 3) of the CRPD:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- (b) Non-discrimination;
- (c) Full and effective participation and inclusion in society;
- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- (e) Equality of opportunity;
- (f) Accessibility;
- (g) Equality between men and women;

The full text of the Mental Capacity Act can be found at:

http://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf

It is very important that the needs and interests of people with intellectual disabilities are not eclipsed by an ideological struggle between social and bio-medical conceptions of intellectual disability. Coming down in favour of one side or the other fails to do intellectual justice to the reality of living with an intellectual disability.

References:

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Appendix:

This submission has been informed by interdisciplinary research undertaken by the CIDDRG over several years. Listed below are a selection of peer-reviewed papers from this research that have informed our thinking.

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- Wong, J.G., Clare, I.C.H., Holland, A.J., Watson, P.C. and Gunn, M.J.** (2000). The capacity of people with a 'mental disability' to make a particular health care decision. *Psychological Medicine* 30: 295-306.
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