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Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road From Guardianship to Supported Decision-Making

By Robert D. Dinerstein*

INTRODUCTION

In deceptively simple language, Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (“CRPD”), Equal Recognition before the law, provides that “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.”¹ If, as is clear from the deliberations that produced this article, Article 12’s use of the term “legal capacity” includes not simply the capacity to have rights (or passive capacity) but also the capacity to act or exercise one’s rights, an important question that arises is how to address the circumstances of individuals with disabilities who may not be able to exercise their legal capacity without some kind of assistance or intervention. Article 12(3) addresses this question in language that once again seems straightforward and uncontroversial: “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”² Yet this use of the word “support,” and the related concept of supported decision making, represents nothing less than a “paradigm shift”³ away from well-established but increasingly discredited notions of substituted decision making. Rhetorical identification of the shift from substituted to supported decision making, however, is one thing; understanding what these terms mean, and fully implementing a regime truly oriented toward supporting rather than supplanting the decision-making rights of people with disabilities, is quite another matter.

To paraphrase one commentator, with Article 12 “on the books,” now comes the hard part.⁴

In this essay, after providing some background on Article 12 and its relationship to core values immanent in the CRPD as a whole, I set out some of the characteristics of guardianship — the primary form of substituted decision making employed around the world — and its alternatives. I then explore the concept of supported decision making and some of the ways in which it has, or might function. Finally, I discuss some of the beginning efforts to come to terms with the meaning of supported decision making in which States Parties, non-governmental organizations, and the Committee on the Rights of Persons with Disabilities are engaged. Early indications are that there continues to be substantial confusion, at least on the part of States Parties, over the

meaning of supported decision making, to say nothing of the fitful process some countries are experiencing in changing their laws to provide for this form of assistance to individuals with disabilities. I will conclude with some observations about steps people with disabilities, NGOs, policy-makers, and others might take to hasten States’ embrace of supported decision making and make the exciting promise of the CRPD a reality for people with disabilities.

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ARTICLE 12 AND ITS IMPORTANCE

As Amita Dhanda⁵ and others⁶ have documented, Article 12 was one of the most hotly contested articles to be considered during the treaty deliberation process. In addition to the controversy surrounding the provision of support, the nature of substituted decision-making arrangements, and the kinds of “due process” protections that should be in place with respect to legal capacity, a key dispute was whether there needed to be a distinction between the legal capacity for rights and the legal capacity to act.⁷ After much back-and-forth discussion, an alternative draft, and a last-minute footnote that purported to reject the concept of legal capacity to act on linguistic grounds, the States Parties adopted Article 12 and its commitment to recognizing legal capacity to the fullest extent.⁸

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Article 12's emphasis on legal capacity and the choice-making that underlies the concept, as well as its statement that "persons with disabilities have the right to recognition everywhere as persons before the law,"⁹ resonates with other important provisions of the CRPD. The Preamble to the Convention recognizes "the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices,"¹⁰ and adds that "persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them."¹¹ Article 3 of the CRPD proper, General Principles, includes "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons" and "full and effective participation and inclusion in society."¹² Article 5's call for equality and non-discrimination emphasizes that "all persons are equal before and under the law" and that States may need to provide reasonable accommodations to ensure that equality and non-discrimination are achieved.¹³ Article 19, Living independently and being included in the community, provides that "States Parties . . . recognize the equal right of all persons with disabilities to live in the community, *with choices equal to others*" and must ensure that "[p]ersons with disabilities have the opportunity to *choose their place of residence* and where and with whom they live on an equal basis with others. . . ."¹⁴ Article 23, Respect for home and the family, requires non-discrimination "against persons with disabilities in all matters relating to marriage, family, parenthood, and relationships, on an equal basis with others" and ensures that people with disabilities of marriageable age have the rights to marry and found a family.¹⁵ Article 26, Habilitation and Rehabilitation, requires States Parties to adopt measures to enable people with disabilities to achieve and maintain "maximum independence" and "full inclusion and participation in all aspects of life."¹⁶ Plainly, if an individual with disability is deemed not to have legal capacity, the person's ability to make choices, achieve maximum independence and be fully included in the community is fatally compromised.

The requirement in Article 12(3) that States Parties provide access to whatever supports people with disabilities need to exercise their capacity reflects the critical insight that even people with the most significant disabilities have legal capacity and are covered by the CRPD. The provision builds on the statement in the Preamble that "recogniz[es] the need to promote and protect the human rights of all persons with disabilities, *including those who require more intensive support*."¹⁷ Article 12(4) expands on the desired characteristics of support by providing that, among other things, capacity-related measures "respect the rights, will, and preferences of the person" and "are proportional and tailored to the person's circumstances. . . ."¹⁸ Article 12 is not the only place in the CRPD where support in one or more forms (including personal assistance) appears; Articles 19 (Living independently and being included in the community), 20 (Personal mobility), 24 (2)(d), (e) (Education), among others, all include references to the need to provide support to people with disabilities.¹⁹ The salience of support is a concrete expression of the social, interactive model of disability that animates the entire Convention and sees disability as not a thing in and of itself but rather as a product of the interaction between an individual and his or her built and attitudinal environments.²⁰

The importance of Article 12's insistence on the recognition of legal capacity of people with disabilities also must be understood in the context of the historical treatment of people with disabilities and their presumed inability to make decisions about their lives. Society assumes that adults of typical intelligence, psychosocial functioning, and sensory ability are able to engage in all aspects of life — deciding where to live, whom (or whether) to marry, how to spend one's money (or to whom to leave it), for whom to vote — on an autonomous basis, with whatever assistance they choose to seek out and consider in their decision making. But for adults with disabilities, the picture has been and continues to be quite different. States have assumed that the mere status of having an intellectual or psychosocial disability (or some sensory disabilities²¹) provides a sufficient basis to presume that the individual is unable to participate fully and autonomously in society, in other words, that the individual lacks the legal capacity to exercise his or her rights. People with disabilities were objects of pity, not people with self-respect.²² In this mode of thinking, people with disabilities need protection, not rights. Guardianship is the primary mechanism through which states have provided this protection; it is a mechanism that, at least in its most complete form, the CRPD, and Article 12, seeks to limit significantly.²³

FROM GUARDIANSHIP TO SUPPORTED DECISION MAKING

Guardianship is a form of surrogate decision making, usually imposed after a court proceeding, that substitutes as decision maker another individual (the guardian) for the individual in question (called variously the ward or the allegedly incapacitated person). Full or plenary guardianship may or may not provide protection to the individual with a disability — there are numerous examples of guardians who have taken advantage of, ignored, or otherwise failed to serve the interests of the person they were supposedly protecting — but even when it is functioning as intended it evokes a kind of "civil death"²⁴ for the individual, who is no longer permitted to participate in society without mediation through the actions of another if at all. Plenary guardianship falsely assumes that incapacity for individuals with disabilities is an all or nothing proposition; that where found it exists in all areas of an individual's life; and that, once found to exist the individual (especially one with an intellectual disability) will not regain capacity at some later time. It fails to recognize that people with disabilities, like people without disabilities, have areas of varying capacity, in different areas of their lives, and at different times.²⁵

In recent years, some states have begun to move away from plenary guardianship as providing more protection than the individual with disability needs, and as being far from the least restrictive manner in which to provide it.²⁶ Alternatives such as durable powers-of-attorney, advance directives, health care proxies, representative payee regimes, direct bank deposit systems, and other modalities can provide more targeted assistance to the individual and at the same time avoid the stigma and indignity of the individual being determined incompetent (or lacking in capacity) for all purposes. Even when some might believe that some form of guardianship is appropriate, limited or partial guardianship is preferable to plenary guardianship in that the court specifically identifies those areas in which the guardian is needed and the individual retains full decision-making capacity in all other areas of his or her life. Other reforms have focused

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on increasing the level of due process that a state must provide before a guardianship can be imposed (*e.g.*, right to a hearing, legal representation, elevated standard of proof, right to confront witnesses and present one’s own witnesses, right to appeal, and provision for periodic review) and have established that the guardian should use the standard of “substituted judgment” when acting on the individual’s behalf — that is, the guardian should strive to determine what decision the individual would make if he or she could do so rather than make the choice that the guardian believes is in the individual’s best interest.

Important as these reforms of guardianship have been, however, they still accept the predominance of a legal regime that locates decision making in the surrogate or guardian and not in the individual being assisted. In contrast, supported decision making, which Article 12 embraces, retains the individual as the primary decision maker, while recognizing that the individual with a disability may need some assistance — and perhaps a great deal of it — in making and communicating a decision. The paradigm shift reflected in the move from substitute to supported decision making aims to retain the individual as the primary decision maker but recognizes that an individual’s autonomy can be expressed in multiple ways, and that autonomy itself need not be inconsistent with having individuals in one’s life to provide support, guidance and assistance to a greater or lesser degree, so long as it is at the individual’s choosing.

SUPPORTED DECISION-MAKING

Supported decision-making can be defined as a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life. Some of the above alternatives to guardianship could be part of a supported decision-making regime, though, to the extent they involve the individual with a disability identifying someone else as authorized to speak for him or her, they can move into a form of substituted decision-making (albeit one that is less restrictive of the individual’s liberty than guardianship). A purer form of supported decision-making would rely on peer support (for example, ex-users of psychiatric services for people with psycho-social disabilities), community support networks and personal assistance,²⁷ so-called natural supports (family, friends), or representatives (pursuant to a representation agreement²⁸) to speak with, rather than for, the individual

with a disability. “What the Convention requires is that the support should be based on trust, be provided with respect and not against the will of the person with disabilities.”²⁹ Countries such as Sweden (through its use of the “god man”³⁰), a number of provinces in Canada,³¹ and Germany³² have made extensive use of supported decision-making arrangements to greater or lesser degree.

Inclusion Europe, an organization that advocates for the human rights of individuals with intellectual disabilities, has issued a Position Paper in which it identifies eight key elements of a system of supported decision-making:

- Promotion and support of self-advocacy.
- Using mainstream mechanisms for the protection of the best interests of a person. Accessibility and accommodation are important.
- Replacing traditional guardianship by a system of supported decision-making (recognizing that there needs to be a transition period from guardianship to support)
- Supporting decision-making. One should look to a formal system of support with registered supporters only for “essential and important decisions of legal relevance.” For many everyday decisions, informal support networks are sufficient and should be used wherever possible.
- Selection and registration of support persons. Jurisdictions need a registration system to reassure those who come into contact with persons with disabilities that the supporters are authorized to assist them. Such a system can also facilitate the training individuals will need.
- Overcoming communication barriers. Augmentative and alternative means of communication must be used when necessary.
- Preventing and resolving conflicts between supporter and supported person.
- Implementing safeguards. These safeguards must ensure that there is a level of proportionality in the support provided.³³

Michael Bach has identified three common elements to supported decision-making models in Canada: (1) they are based on a set of guiding principles that emphasize the person with disability’s autonomy, presumption of capacity, and right to make decisions on an equal basis with others; (2) they recognize that a person’s intent can form the basis of a decision-making process that does not entail removal of the individual’s decision-making rights; and (3) they acknowledge that individuals

with disabilities will often need assistance in decision-making through such means as interpreter assistance, facilitated communication, assistive technologies and plain language.³⁴

Supported decision making thus permits vindication of Article 12's imperative that all people with disabilities retain their legal capacity, even those who may need significant and intensive support to effectuate it. But whether countries move toward adopting it in lieu of substituted decision-making regimes depends in the first instance on how they interpret their practices with respect to Article 12 and how treaty bodies and non-governmental organizations respond to those interpretations.

IMPLEMENTING SUPPORTED DECISION-MAKING UNDER ARTICLE 12: THE HARD PART BEGINS

Under Article 4 of the CRPD, States Parties are obligated "to adopt all appropriate legislative, administrative and other measures for the implementation of the rights" in the CRPD and "to take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities."³⁵ To the extent a state provides only for plenary guardianship and makes no provision to assist people with disabilities to obtain the supports they need for decision-making, their laws would seem in clear violation of Article 12.

Article 34 of the CRPD created an expert committee, the Committee on the Rights of Persons with Disabilities ("the Committee"), to review and comment upon the activities of States Parties to the CRPD.³⁶ Pursuant to Article 35 (1), States Parties must file with the Committee "a comprehensive report on measures taken to give effect to its obligations under [the CRPD] and on the progress made in that regard" within two years after the CRPD enters into force for that country.³⁷ To date, the Committee has met for six sessions, with a seventh scheduled for April 16-20, 2012.³⁸ The Committee has adopted

Concluding Observations on two countries — Tunisia (at its Fifth Session) and Spain (at its Sixth Session) — and has received reports from 26 other countries (or sub-country entities) as of the upcoming Seventh Session. At the Seventh Session, the Committee expects to adopt Concluding Observations on Peru, and will adopt a list of issues for Argentina, China and Hungary. Thus, the work of interpreting and implementing the CRPD is in its very early stages.

The States Parties reports to the Committee from Tunisia and Spain reflect that those countries' governments may not truly understand the difference between substituted and supported

decision-making. Tunisia reported that it permits guardianship on the grounds of "insanity, mental impairment or profligacy."³⁹ The State said nothing about whether it provided for supported decision-making or, if not, what its plans were for moving toward adoption of such a scheme. The report on Tunisia by the International Disability Alliance noted that "Tunisia does not understand supported decision-making,"⁴⁰ and another non-governmental organization, Atlas Council, also was critical of Tunisia's compliance with Article 12.⁴¹ Tunisia's response to the Committee's List of issues (which included questions regarding the application of legal capacity, the kinds of guardianship, and whether there were any measures to move toward supported decision making) showed no greater understanding of the issue.

In its Country Report, Spain, in Paragraph 53, claimed to be in compliance with Article 12(3)'s requirement of providing access to supports because it had guardianship statutes!⁴² It reported that a finding of incapacity could be made on the basis that the person could not act "unaided."⁴³ It proposed to change its terminology from deprivation of legal capacity to modification of legal capacity, maintaining that this change in nomenclature would constitute compliance with the CRPD.⁴⁴ The non-governmental organization CERMI⁴⁵ stated more directly that Spanish

laws did not provide for supported decision-making.⁴⁶ Once again, the Committee's list of issues identified guardianship practices as a cause for concern under Article 12; it requested Spain to report on the number of people under guardianship and the number of rulings modifying an individual's capacity to act; to explain how an individual subject to guardianship was sufficiently protected given the absence of statutory language addressing the guardian's potential undue influence on or conflict of interest with the ward; and to report on any measures designed to replace substituted decision-making with supported decision-making.⁴⁷ Spain's response essentially indicated that it is the court's responsibility to protect the interest of the individual under guardianship.⁴⁸

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Notwithstanding these disappointing state reports, the good news is that the Committee's Concluding Observations for both Tunisia and Spain reflect its understanding of Article 12 and its commitment to keep the focus on supported decision-making. At its Fifth Session, with regard to Tunisia's compliance with Article 12, the Committee stated that it was "concerned that no measures have been undertaken to replace substitute decision-making by supported decision making in the exercise of legal capacity" and went on to recommend that Tunisia review its guardianship laws "and take action to develop laws and policies to replace regimes of substitute decision-making by supported

decision-making.”⁴⁹ It added that relevant public officials and other stakeholders should receive training on this issue. At its Sixth Session, the Committee made the same recommendation to Spain in its Concluding Observations regarding the review of state guardianship laws and their replacement by supported decision making (adding that the latter “respects the person’s autonomy, will and preferences.”).⁵⁰ In preparation for the upcoming Seventh Session, in which it expects to issue its Concluding Observations on Peru, the Committee propounded among its list of issues a question that asked the state to: indicate the number of people with disabilities under guardianship (as a percentage of all people with disabilities in the country); provide information on the legal criteria for guardianship and any procedures for challenging decisions ordering it; and clarify the meaning of the concept of people “unable to look after themselves due to a mental or physical disability.”⁵¹

Furthermore, at least some of the countries who have filed reports but that have not yet been on the Committee’s agenda do seem to recognize that their existing legislation or practice is at odds with Article 12. For example, Argentina has reported that its legislation does not comport with Article 12 because it does not provide for supported decision-making.⁵² Hungary reported on a statute that adopted provisions abolishing guardianship in favor of supported decision-making, but noted that the statute did not come into force.⁵³ Both Australia⁵⁴ and Austria⁵⁵ contend that substituted decision making is used as a last resort. Ireland has identified legal capacity as a crucial issue to address in connection with its efforts to ratify the CRPD, recognizing that its 1871 Lunacy Regulations are in dire need of attention.⁵⁶

Outside of the CRPD process, other countries are making strides toward addressing their laws for protecting the legal capacity of individuals with disabilities. According to the website of Mental Disability Advocacy Centre (“MDAC”), an organization that closely monitors developments in Europe in the area of legal capacity, Bulgaria, which only recently ratified the CRPD, has formed a task force on legal capacity law reform.⁵⁷ The Czech Republic recently enacted (February 20, 2012) a new civil code that introduces supported decision making and views restriction on legal capacity as a last resort. According to MDAC, the Czech Republic is the first country to enact legal capacity reform based on the CRPD.⁵⁸

CONCLUSION: NEXT STEPS

To be sure, the above actions are nascent, and, in some cases, seem to represent a “two steps forward, one step back” approach to the legislative and regulatory change needed to implement Article 12. Nevertheless, states interested in complying with Article 12, or at least assessing the extent to which their existing legislation falls short of its mandate, can look to a variety of sources for inspiration in addition to the efforts the above states are undertaking. Even before the CRPD was adopted, the Montreal Declaration on Intellectual Disabilities, issued in 2004, called for supported decision making for people with intellectual disabilities.⁵⁹ As noted above,⁶⁰ the International Disability Alliance has issued a Legal Opinion on Article 12. The United

Nations High Commissioner for Human Rights’ Thematic Study on enhancing awareness and understanding of the CRPD sets out clear (if not uncontroversial) views about Article 12’s reach.⁶¹ More recently, the European Commissioner for Human Rights’ report, *Who Gets to Decide?*, calls on member states of the Council of Europe to abolish mechanisms for full incapacitation and plenary guardianship and adopt supported decision-making standards.⁶² Entities as disparate as a Surrogate Court judge in New York City⁶³ and the Inter-American system’s Committee for the Elimination of All Forms of Discrimination Against Persons with Disabilities⁶⁴ have cited to Article 12 as persuasive authority in examining, respectively, a guardianship proceeding and the meaning of the Inter-American disability convention. Litigation brought before domestic courts and human rights commissions and courts; conferences and workshops featuring experts from around the world; foundations supporting international disability rights; non-governmental organizations (including those producing alternative reports for states reporting to the CRPD’s Committee); and, perhaps most importantly, people with disabilities themselves are important resources for assisting states that truly want to understand what supported decision making really means and why it is critical if Article 12 is to be implemented.

In addition, as the Committee itself has recognized, it is critical that states provide training for policy-makers and relevant stakeholders (including people with disabilities themselves, as well as governmental officials, health care personnel, and the business community, who come into contact with people with disabilities) on the meaning of supported decision-making — training that is concrete and practical as well as grounded in a solid philosophical and legal framework of autonomy, equality and non-discrimination. The reports of states that think they are providing supported decision making through guardianship suggest that there is much training work to accomplish. But even if supported decision-making is a relatively new concept within international human rights, it has been operating in some countries, such as Canada, for over 20 years. There is wisdom to be tapped.

The responsibility for implementation of the CRPD is not limited to the actions of States Parties. Article 33’s requirement that States Parties establish national implementation and monitoring mechanisms, with participation by civil society (including people with disabilities and their representative organizations), provides an opportunity for individuals and groups to keep a watch on states’ compliance with the Convention, and can provide an important source of information to the Committee. Finally, for those states that adopt the Optional Protocol,⁶⁵ the filing of individual complaints can serve to encourage compliance with the CRPD.⁶⁶

Enacting appropriate state legislation, and monitoring compliance with the CRPD, will not transform decision-making regimes from substituted to supported decision-making overnight, but they are a start. The human rights of people with disabilities demand that we not delay in making sure the paradigm shift represented by Article 12 becomes a reality.