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Response to Draft General Comment No. 1 on Article 12 UN Committee on the Rights of Persons with Disabilities

Submitted by
Canadian Association for Community Living

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**Diversity includes.
On se ressemble.**

Introduction¹

The Canadian Association for Community Living (CACL) is a national association in Canada of over 40,000 members, over 300 local and 13 provincial/territorial associations and the national organization. Our mission is to advance the full inclusion, human rights, equality and citizenship of people with intellectual disabilities and their families. CACL has worked for over twenty years to develop the concept of supported decision making and alternatives to guardianship.

CACL is grateful to the Committee on the Rights of Persons with Disabilities for its leadership in developing a Draft General Comment (GC) on Article 12 to provide guidance to States Parties in interpreting this Article and in meeting State Party obligations with respect to ensuring equal recognition before the law. We also commend the Committee for its inclusive, participatory and consultative approach to the development of the General Comment.

In general, CACL is supportive of the guiding principles articulated in the Draft GC, though with some distinctions as discussed below. However, we believe the Draft GC as written does not provide sufficient guidance to States Parties in dealing with what may be difficult challenges of supporting people with significant intellectual disabilities to exercise their right to legal capacity. This is primarily because interpretation of a person's will and preferences is not always as straightforward as the Draft GC appears to assume. There are often profound difficulties in interpretation of will and preference depending on the nature of a person's unique intellectual characteristics and developmental path, and often conflicting interpretations as a person's will and preference can appear to change radically over time. This will leave some persons in a context of interpretive indeterminacy on the part of others. A principle of proportional support is not the answer to these challenges, except at the highest and most abstract level of principle. Different types of support, and the extent of supports provided, have different legal consequences, and we believe the General Comment should give greater guidance to States Parties in this regard to ensure full compliance with Article 12. Our submission elaborates on these general points in respect of specific paragraphs in the Draft GC, and is organized accordingly.

In short, we commend the Committee for taking on this task, and we urge it to more fully address the challenges in recognizing, respecting and promoting the fundamental right to legal capacity.

¹ This submission is based on extensive work done by the CACL Working Group on Legal Capacity and Supported Decision Making, which has prepared a draft statutory model for advancing and protecting the right to legal capacity.

Article 12, paragraph 2

11. We are guided in our work to advance the right to legal capacity by the definition in the background paper prepared by the Office of the High Commissioner for Human Rights for the Ad Hoc meetings drafting the UN *Convention on the Rights of Persons with Disabilities*:

Legal capacity includes the ‘capacity to act’, intended as the capacity and power to engage in a particular undertaking or transaction, to maintain a particular status or relationship with another individual, and more in general to create, modify or extinguish legal relationships.²

We would suggest replacing or enhancing the definition in the Draft GC which defines legal capacity to mean recognizing the ‘person as an agent who can perform acts’. We are concerned this language on its own might be read restrictively, with its focus on ‘performance’ and that the definition should reference the ‘person as an agent with the power to engage in transactions and in general to create, modify or extinguish legal relationships.’ The exercise of the power, in practical terms, may for some individuals require others to execute and ‘perform’ various steps to give the power effect, and the definition of legal capacity should keep open that possibility.

12. CACL appreciates the direction provided in the Draft GC in rejecting the usual conflation of legal capacity and mental capacity. That said, we believe there are substantially different ways of exercising legal capacity and that States parties must recognize these. We believe that maintaining in law a distinction between exercising one’s legal capacity legally independently and exercising it with the support of others who are legally recognized to provide that support, is crucial. For the sake of clarifying, and in general terms, we can think of people exercising their legal capacity in two broadly different ways, and people can be vulnerable in substantively different ways depending on the manner in which they do so.

First, some people with intellectual disabilities make their decisions legally independently, provided they have the supports (plain language, informal assistance, communication technologies, etc.) and accommodations in the decision-making process by third parties that may be required to demonstrate they can understand and appreciate the nature and consequences of a decision. This group can be vulnerable in exercise of their legal capacity

² Office of the United Nations High Commissioner for Human Rights, “Legal Capacity: Background conference document” (2005), online: <http://www.un.org/esa/socdev/enable/rights/ahc6documents.htm>.

because they lack the supports and accommodations needed to demonstrate to others that they can act independently.

Other people with more significant or ‘profound’ intellectual disabilities will require other persons (decision-making supporters) who can understand their unique forms of communication to assist them in developing their will and preferences, and to translate them into particular actions and decisions which enable the person to exercise legal capacity. We attach the term ‘supported decision making’ uniquely to these types of arrangements. This group is particularly vulnerable to the imposition of decisions by others whom they require to interpret their will and preference. Such persons may be trusted family, friends and service providers – who provide support with the best of intention but in a way that may end up reproducing paternalism in the interests of protection.

For the first group of individuals with intellectual disabilities we want to ensure that Article 12 provides them the ground on which they can clearly say that they can make their own decisions ‘by themselves.’ For third parties to enter legal relationships and transactions with these individuals and to recognize and respect those decisions, especially financial institutions and health care providers, they will need to be assured that the individuals understand the nature of the decision and can appreciate the consequences. This is the basis of decision making that ‘others’ referred to in Article 12.2 are subject to. For the second group of individuals States parties must ensure they have access to legally-recognized decision-making supporters who ensure persons can exercise their legal capacity according to their will and preferences.

Both ways of exercising legal capacity are valid, and we urge the Draft GC to recognize this distinction. States parties should be guided to ensure domestic laws recognize that persons can exercise legal capacity, which includes giving informed consent in two basic ways: 1) by themselves, if they have the requisite decisional abilities to understand and appreciate on their own, with supports and accommodations as may be necessary; or 2) with the support of others who play a role in interpreting a person’s will and preferences and translating that will and preference into a specific health care decision. To recognize that people have different decisional abilities is not in itself discriminatory; just as it is not discriminatory to recognize that people have different mobility abilities. The issue is how those different abilities are recognized and supported, and how to ensure equal access and outcomes are not dependent on those differences.

The importance of this distinction is clear in health care decision making, for example. We should not conflate legal capacity with mental capacity. But nor should we conflate provision of plain language by a physician in the process of obtaining informed consent from a woman with an intellectual disability who wishes a tubal ligation, with recognition of support persons whose

role is to interpret the will and preference of a woman with a profound intellectual disability and apply it to the same health care decision. These are two very different situations. Both women have full legal capacity but they exercise it differently. Surely, there must be additional safeguards in the second situation, when the physician only has the interpretation of support persons to go by because s/he is unable to understand or communicate directly with the woman patient.

Legal regimes the world over require that some version of this understand and appreciate test be in place to protect autonomy of individuals, and to help draw the line between those who choose situations which others may see as exploitative or outside the bounds of community acceptance (but not criminal), and those who are forced into exploitative situations they would not choose and that in no way accords with their will and preferences – as is the case for far too many people with intellectual disabilities. The only basis for ensuring that protection is to draw a line in the law that can be adjudicated and that provides for persons to clearly say: they know what they are doing, they are choosing dignity of sometimes substantial risk, and they choose it despite what others think, what their parents or ‘community’ agree with. We provide ramps into buildings because we recognize that people exercise their mobility in different ways. We want to ensure that when people exercise their legal capacity only through the interpretive acts of designated support persons, sufficient safeguards and design guidelines are in place, just as we expect with architectural features aimed at providing universal access.

To provide for this second way of exercising legal capacity clear safeguards will be required: legislated duties for support persons in such situations; a process of appointment where the only basis of appointment is that witnesses can attest to a trusting relationship between a person with a significant or ‘profound’ intellectual disability and those who are asking to be recognized as decision-making supporters; and processes to adjudicate disputes about who is to be a decision-making supporter, how to interpret will and preference when interpretations conflict. This is increasingly important with the fastest growing group of persons with disabilities in many countries being older persons who lose cognitive and physical functions they once had, and who face substantial risk of financial and other forms of abuse at the hands of their carers and decision-making supporters.

Article 12, paragraph 3

15-16. The discussion above relates to supports in decision making, the focus of Article 12.3 but our point was to demonstrate that the State parties should be given greater guidance in the GC that people can exercise and enjoy legal capacity in very different ways.

We agree with the statement in paragraph 15 of the Draft GC that ‘support’ is a broad term that encompasses both informal and formal arrangements. But the Draft GC in these paragraphs appears to gloss the legal distinctions that should be made. Ensuring that a physician respects a person’s right to bring others into the doctor’s office to support a person in health care decision making, is quite different from a physician having to decide which of the ‘trusted’ persons he or she should listen to when they are the only ones who can interpret the will and preferences of a person who has a significant intellectual disability, and how these should be applied in the circumstance. Again, greater clarity is needed on the distinct legal ramifications of different types of support arrangements, and the safeguards that should attend upon them.

We urge the Committee to bring the lens also of persons with significant intellectual and cognitive disabilities to the drafting of the GC, persons who may only have one other person in the world who can understand and interpret them, and even at that the support person faces daily indeterminacy in interpretation; and people who have no one in their lives in a relationship of trust and who can understand their will and preferences, at least at one point in time.

In this regard, we suggest the Draft GC recognize that there are and will always be situations where a person’s will and preference cannot be interpreted with any degree of certainty – either because of absence of prior planning documents/indications, or because a person has been so isolated and excluded s/he has no one whom they trust and who can learn their form of communication, at least in the short term. Substitute decision making systems are in place to deal with this type of situation, and State parties will likely defend their provision given their obligations to protect vulnerable persons.

In recognizing the reality of such situations, we recommend that GC advance the notion of ‘best interpretation of will and preference’ to replace the best interest test for application in these situations. Such a test would recognize that will and preference cannot always be interpreted with certainty, but that there are always better interpretations than others. Further, to guide that States parties abide by such a test in facilitating the making of needed decisions for a person in such a situation. In effect, this would be a third way that persons could exercise their legal capacity where no provision of support is available that could enable a person to clearly direct decision making. CACL has termed this way of exercising legal capacity ‘facilitated’ decision making to provide a basis on which to terminate substitute decision making regimes, and at the same time provide for the greater safeguards States parties should be obligated to provide in such situations.

Obligations of State parties

26. We appreciate the spirit in which this paragraph is drafted; however, we are very concerned that to exclude Article 12 entirely from provisions for progressive realization may have the effect of States parties minimizing rather than maximizing their obligations. Certainly, the recognition of the right to exercise and enjoy legal capacity without discrimination on the basis of disability and on an equal basis with others, as per paragraphs 1 and 2 of Article 12 is paramount, and should apply immediately. But to suggest that the obligations under 12.3 must be immediately realized upon ratification, seems very much at odds with the analysis in the preceding sections of the Draft GC. There is recognition throughout the Draft GC that for some individuals the supports they require will be of a relational nature, trusting personal relationships. What does it mean to say that States parties must ensure such supports are in place at the moment of ratification? That all persons have intimate, close friends who know them personally and can help interpret them to the world? And this is to be expected upon ratification for persons who are among the most excluded and victimized?

No country in the world is at a stage where the extent of supports required for persons with disabilities to exercise legal capacity on an equal basis with others is fully in place. Moreover, we have so much to learn about what support arrangements work best in what situations and how they are to be nurtured, keeping ethno-racial-cultural diversity in mind, as well as the vastly different economic conditions and fiscal realities at play in different countries. By suggesting that Article 12.3 is not subject to progressive realization, we are concerned that States Parties will not be held accountable for establishing plans, benchmarks, evaluation systems, and reporting on their progress in ensuring access to supports required for all persons to fully exercise and enjoy legal capacity.

Much more fruitfully we suggest, Article 12.3 should be interpreted as a basic and fundamental obligation which requires sustained progressive realization. The principle of ‘progressive realization’ does not mean that governments are excused from acting to implement the provisions of the CRPD. On the contrary, it does mean “that a State’s compliance with its obligation to take appropriate measures is assessed in light of the resources – financial and others – available to it.”³ We suggest this understanding be applied to Article 12.3.

As stated by the OHCHR, States parties must make constant effort to improve the enjoyment of recognized and protected rights, and such steps “should be deliberate, concrete and targeted

³ See Office of the United Nations High Commissioner for Human Rights, “Frequently Asked Questions on Economic, Social and Cultural Rights, Fact Sheet No. 33” (2008, available online: <http://www.ohchr.org/Documents/Publications/FactSheet33en.pdf>).

as clearly as possible, using all appropriate means.” The Office suggests that in order to meet these obligations within the context of progressive realization, governments should:

- assess the current state of enjoyment of rights;
- formulate strategies and plans, with indicators and time-bound targets;
- adopt necessary laws and policies, and allocate necessary resources;
- regularly monitor and assess progress; and
- establish grievance mechanisms so individuals and organizations can lodge complaints if the government is not meeting its responsibilities.⁴

The OHCHR has also established that “Even if a State has clearly inadequate resources at its disposal, the Government must still introduce low-cost and targeted programmes to assist those most in need so that its limited resources are used efficiently and effectively.”⁵

In summary, we believe this framework for progressive realization provides a much more robust approach to ensuring States parties actually make progress on ensuring access to supports needed, than to simply state by definitional fiat that such supports must be fully realized upon ratification.

⁴ *Ibid.*

⁵ *Ibid.*