

Discussion Paper for Side Event at UN Open-ended Working Group on Ageing

Perspectives from the drafting of the UN Convention on the Rights of Persons with Disabilities

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Introduction

As the world's population ages, more and more discussion has emerged concerning the human rights of older people. Statistics from WHO Global Report on Disability (published in June 2011)¹ demonstrate the high proportion of people with disabilities who are now reaching old age, compared with even ten or twenty years ago. The establishment of the UN Open-ended Working Group on Ageing is a significant step towards formulating a comprehensive international document which recognises the rights of older people and requires States to protect these rights at domestic level. Many of the core rights of older people for which recognition is sought closely reflect the provisions of the UN Convention on the Rights of Persons with Disabilities (CRPD), which was adopted by the UN General Assembly in December 2006.

Obligations on States to respect, protect and fulfil the rights of older people with disabilities are already set out in the CRPD, and the Open-ended Working Group on Ageing presents the opportunity to ensure that these core rights are extended to all older people. Some rights in the CRPD that have particular relevance for older people include legal capacity (Article 12), the right to live independently and be included in the community (Article 19) and freedom from exploitation, violence and abuse (Article 16). This paper provides an analysis of these three articles, their evolution through the CRPD drafting process, their significance for older people, and opportunities for future progress in advancing these rights through the new Working Group on Ageing.

In addition, the drafting process for the CRPD also merits examination in itself, especially the high levels of civil society involvement by disabled persons' organisations (DPOs) – and the move towards meaningful inclusion of people with disabilities on government delegations at the drafting sessions. The experience of the International Disability Caucus, a diverse group of DPOs which became a *de facto* negotiator in the drafting process, will be discussed below, with some perspectives on the challenges of working together, the opportunities for engagement with key decision-makers and the outcomes of the drafting process for those who participated.

This paper is intended to form the basis for further discussion at the Second Session of the UN Open-ended Working Group on Ageing in New York from 1-4

¹ *World Report on Disability* (Geneva: World Health Organization, 2011) Available at: http://www.who.int/disabilities/world_report/2011/en/index.html.

of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

The text of Article 12(1)-(2) reaffirms recognition before the law and universal legal capacity for all persons with disabilities, “on an equal basis with others in all aspects of life”. This represents a clear move away from systems of substituted decision-making (such as guardianship) in which legal capacity is deprived totally or restricted partially. Significantly, Article 12(3) places a requirement on States to provide support to enable individuals to exercise their legal capacity – a core commitment which is also particularly relevant to older people who may seek assistance in decision-making from trusted individuals, for example family members or support networks.

Given the contested issues at stake, the text of Article 12(4) contains some compromises. Although many disability rights advocates hold the view that the CRPD outlaws any form of substitute decision-making⁴ the text of the Article itself does not explicitly prohibit substituted decision-making models, and Article 12(4) and (5) may also be read to suggest that such forms of decision-making are permissible if subject to safeguards (e.g. that any restrictions on an individual’s legal capacity should apply for the shortest time possible, be subject to independent review, etc.)

Gerard Quinn has identified six conceptual issues arising from Article 12,⁵ and these are a useful starting point for discussions about how the right to legal capacity can be progressed by the Open-ended Working Group on Ageing. His first issue concerns the phrase “on an equal basis with others” in Article 12(2). Many of the contentious articles in the CRPD contain this phrase, and it can be viewed as a double-edged sword – as it can be interpreted progressively to ensure disabled people have access to the same rights as the rest of the population; or conservatively, to mean that if the general population’s legal capacity is restricted, then so will that of disabled people. The second issue is whether Article 12(2) contains an irrebuttable presumption of legal capacity to exercise rights. This debate about capacity for rights versus capacity to act, or exercise rights, is one which was hotly contested in the drafting process, and almost halted agreement of the final CRPD text.⁶

Thirdly, the question of whether substituted decision-making is ever permissible under Article 12 also arises from one reading of Article 12(4). A related fourth issue is whether some elusive point exists where “supported decision-making” amounts to “substituted decision-making.” This issue is brought into focus when

⁴ See for example, World Network of Users and Survivors of Psychiatry, “Position Paper on the Implications of the CRPD”, 14 March 2011, available at <http://wnusp.rafus.dk/wnusp-releases-statement-on-the-implications-of-the-crpd-on-forced-treatment.html>.

⁵ Quinn, G., “Centering People Over Their Own Lives” (Galway: Summer School From Paper Rules to Action, Centre for Disability Law and Policy, NUI Galway & Harvard Project on Disability, 8 June 2011).

⁶ See Dhanda, A., “Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future” (*Syracuse Journal of International Law & Commerce*: Vol 34, 429, 2006-2007).

However, throughout the drafting process,¹⁰ it was argued that this right to independent living should not become a justification for the isolation or victimisation of people with disabilities who live in the community with their non-disabled peers, or the removal of State support to facilitate participation and inclusion in community life. Concerns were also raised about ensuring that people with disabilities could continue to live with in the community with their families if they so wished, and the need for state support to families to achieve this. Given these challenges, the inclusion of Article 19 in the CRPD is a major achievement.

Some of the key commitments in Article 19 which are relevant to people with disabilities and older people alike are as follows:

- **Choice.** the right to live in the community with choices equal to others, the right to choose where and with whom to live (Article 19(a));
- **Disability-specific services.** This includes “access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community” (Article 19(b)); and
- **Accessible regular services.** This includes the availability on an equal basis to people with disabilities of “[c]ommunity services and facilities for the general population”, which should be “responsive to their needs”.

The success of Article 19 is also due in large part to sustained advocacy by DPOs throughout the drafting process. These organisations and advocates insisted that the inclusion of Article 19 was key to the entire Convention, that it fulfilled the promise of ‘nothing about us without us’ on the basis of which DPOs had participated in the drafting process, and provided the essential tools to combat the kinds of invidious discrimination which people with disabilities had been subject to at state level (e.g. with respect to access to housing and in-home supports).¹¹

The CRPD protects Article 19 rights and freedoms for all people with disabilities, including older people with disabilities, and through the work of the Open-ended Working Group on Ageing, it may be possible to extend this recognition to all older people so as to prevent the congregated institutionalization of older people, simply on the basis of their age, a growing phenomena in many parts of the world. A key argument in progressing these rights, and one which was repeated throughout the work of the Ad Hoc Committee which drafted the CRPD, is that the CRPD contains no new rights, but draws on existing international human rights norms, packages them and applies them to the particular circumstances of people with disabilities. We recommend that a similar approach be taken by the Open-ended Working Group on Ageing, building on the

¹⁰ The archive of the negotiations on the Convention on the Rights of Persons with Disabilities is available at: <http://www.un.org/disabilities/default.asp?id=1423>.

¹¹ Lord, J., & Kayess, R., “Living Your Own Life” (Galway: Summer School From Paper Rules to Action, Centre for Disability Law and Policy, NUI Galway & Harvard Project on Disability, 8 June 2011).

Article 16(2) then highlights the need for gender and – of particular relevance for the Open Ended Working Group on Ageing – age-sensitive assistance and support for people with disabilities who have experienced violence, exploitation and abuse. Also set out is the obligation to provide information and advice for people with disabilities, families, and caregivers on how to identify and report suspected abusive practices. The inclusion of the requirement to provide assistance which is not only disability-sensitive and fully accessible, but also sensitive to age and gender is particularly welcome.

Article 16(3) emphasises the need for States to ensure the independent monitoring of programmes and services, so that violence, exploitation and abuse can be prevented, addressed and dealt with. Such monitoring is particularly significant, as in many cases, the lack of an effective complaints mechanism, and the failure to take the evidence of people with disabilities seriously, has resulted in serious inequities in accessing justice for people with disabilities. This provision echoes that in the Optional Protocol to the UN Convention against Torture, which obliges States to set up independent bodies to carry out regular visits to places of detention.

Fourthly, Article 16(4) highlights the need for recovery, rehabilitation and reintegration into society of persons with disabilities who experience violence, exploitation or abuse – and requires States to facilitate this recovery in a gender and age-sensitive manner. Finally, Article 16(5) contains a requirement on States to introduce effective legislation and policies to investigate, identify, and prosecute instances of violence, exploitation and abuse of people with disabilities.

The framing of Article 16 of the CRPD, and in particular its constant emphasis on the need for laws, policies and programmes which are age and gender-sensitive, provides a highly useful model for the Open-ended Working Group on Ageing. For the first time in international human rights norms, practices which are exploitative, violent or abusive but do not amount to torture, cruel, inhuman or degrading treatment, are explicitly prohibited, and States are obliged to take concrete steps to combat these practices where they exist.

Insights from Civil Society on the Drafting Process of the CRPD

Regarding the drafting process of the CRPD, Kayess and French note as follows:

The CRPD negotiations are reputed to have involved the highest level of participation by representatives of civil society, overwhelmingly that of persons with disability and disabled persons organisations, of any human rights convention in history. Indeed, the formulation and future implementation of the CRPD has been framed repeatedly both by governmental and non- governmental actors as a continuing partnership between the UN and disabled persons throughout the world, based on the principle of ‘nothing about us without us’.¹⁵

¹⁵ Kayess, R. and French, P., “Out of Darkness Into Light? Introducing the Convention on the Rights of Persons with Disabilities” (2008) 8(1) *Human Rights Law Review* 1, 3-4.

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<http://www.nuigalway.ie/cdlp> (a member of the Lifecourse Institute,
<http://www.nuigalway.ie/lifecourse>)
Disability Rights International – <http://www.disabilityrightsintl.org>
Human Rights Watch – <http://www.hrw.org>
Inclusion International – <http://www.inclusion-international.org>
Mental Disability Advocacy Center – <http://www.mdac.info>
Rehabilitation International – <http://www.riglobal.org>