



**Comments on the
Chair's Text for the
Draft Comprehensive and Integral
International Convention on the
Protection and Promotion of the Rights
and Dignity of Persons with Disabilities**

19 December 2005

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Introduction

The National Association of Community Legal Centres

The National Association of Community Legal Centres is the peak body for 180 community legal centres (CLCs) located throughout Australia in urban, regional and remote locations. Through NACLCL, CLCs collaborate on joint projects of mutual interest to their clients and communities. This submission is one such collaboration.

This submission was prepared by the NSW Disability Discrimination Legal Centre (DDLC), the Public Interest Advocacy Centre (PIAC) and Australian Lawyers for Human Rights (ALHR).

It has been adopted by the NACLCL.

NSW Disability Discrimination Legal Centre

The NSW Disability Discrimination Legal Centre was established in 1994 to help people with disability understand and protect their rights under disability discrimination laws.

The Public Interest Advocacy Centre

The Public Interest Advocacy Centre is an independent, non-profit legal and policy centre. PIAC provides legal advice and representation, public policy programs and advocacy training to promote the rights of disadvantaged and marginalised people and enhance accountability, fairness and transparency in government decision-making.

Australian Lawyers for Human Rights

Australian Lawyers for Human Rights is an association with a membership of over one thousand Australian lawyers committed to promoting awareness of and adherence to human rights in Australia. ALHR is an unfunded association that relies on the efforts of its members to engage in public policy debates that affect the protection and promotion of human rights at a domestic level.

The United Nations convention development process

In December 2001, the General Assembly of the United Nations assented to a resolution to establish an Ad Hoc Committee to consider proposals for a Comprehensive and integral international convention on the rights and dignity of persons with disabilities. Six sessions of the Ad Hoc Committee have been held to date. At its Second Session, the Ad Hoc Committee achieved consensus that a specific thematic convention dealing with the human rights of persons with disability would be developed, and established a Working Group to develop a draft text proposal for such a convention. This task was completed in January 2004.

In its following four sessions, the Ad Hoc Committee has undertaken an extensive First and Second Reading of the Working Group's draft text, and many proposals for amendment have been made by participating member States, non-government organisations, and national human rights institutions. At the end of the Sixth Session, the Ad Hoc Committee approved a proposal that its Chair, the New Zealand

Ambassador to the United Nations, New York, His Excellency Don MacKay, develop a synthesised text that reflects the work of the Ad Hoc Committee to date. This 'Chair's Text' will form the basis of further negotiations.

On 7 October 2005, His Excellency Don MacKay provided his draft text under cover of an open letter to the Ad Hoc Committee.

Consultation process

The NACLC welcome the opportunity to comment on the Chair's Text for the Draft Comprehensive and Integral Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (**the Draft Convention**).

The NACLC acknowledges that the Draft Convention is the result of many weeks of debate and negotiation between member states and, as such, will always represent something of a compromise position.

The NACLC is of the opinion that the Draft Convention is a significant improvement on previous drafts. However, the NACLC make the following recommendations with the aim of improving both the readability and the effect of the Draft Convention.

Summary of Recommendations

Recommendation 1

That the position that no definition of disability is required in the Convention be revised and replaced with an inclusive definition of disability that relies on the 'impairment' and 'disability' elements of the social model and reflects the definition in the *Disability Discrimination Act 1992*.

Recommendation 2

That the definition of 'discrimination on the basis of disability' in Article 2 be amended to include distinctions, exclusions or restrictions on the basis of past, future or imputed disabilities as well as current.

Recommendation 3

That the current definition of 'reasonable accommodation' in Article 2 be replaced with the following language:

'Reasonable accommodation' means necessary and appropriate modifications and adjustments needed, in a particular case, to ensure to persons with disabilities the enjoyment or exercise on a basis of equality with others of all human rights and fundamental freedoms including those set out in this Convention.

Recommendation 4

That the Draft Convention be amended to include, wherever there is an obligation to reasonably accommodate, that the limit on that obligation is based on the principle of unjustifiable hardship.

Recommendation 5

That the Draft Convention include a general interpretive article recognising the impact that results from the intersection of disability with particular personal characteristics or special circumstances.

Recommendation 6

That in the alternative to Recommendation 5 that the Draft Convention incorporate specific articles aimed at the particular disadvantage of women, children and Indigenous people with disabilities, and of people with disabilities from racial, ethnic or religious minorities.

Recommendation 7

That Article 12(2) be amended to ensure the express recognition of the right to reasonable accommodation in the exercise of legal capacity.

Recommendation 8

That the text '[legal capacity]' be included in Article 12(2) and the words 'the capacity to act' be deleted with 'that capacity' retained.

Recommendation 9

That the terms 'supported decision making' and 'substituted decision making' be used in Article 12(2).

Recommendation 10

That serious consideration be given to a restructure of Article 12(2) to set out the obligation to provide reasonable accommodation for the exercise of legal capacity in the head paragraph of the article, and to set out the principles to guide both supported and substitute decision making in one sub-paragraph, and the principles to govern appointment, monitoring and review of supported and substituted decision making in a second sub-paragraph.

Recommendation 11

That an interpretive Article that defines consent to include the consent available through substituted or supported decision-making be included in the Draft Convention.

Recommendation 12

That the option of participating in clinical trials with consent and with prior approval of the trial or equivalent by an independent judicial or quasi-judicial decision-making body be included.

Recommendation 13

That Article 17 be amended to remove the use of the terms 'involuntary' and 'forced', and for the Article to be redrafted to the extent necessary to use the term 'without consent'.

Recommendation 14

That a new paragraph be included in Article 17 to provide safeguards to ensure that any intervention contemplated within paragraph 17(2) with consent be subject to a requirement that it be approved by an independent court or tribunal in accordance with law, with the application of appropriate legal safeguards and consistent with the Convention and international human rights law.

Recommendation 15

That Article 17(4) be modified to refer to any form of intervention (whether it be with consent or without), and that sub-paragraph (b) of Article 17(4) be removed, but all of the remaining safeguards be retained.

Recommendation 16

That Article 21(e) be amended to read 'developing, recognising, promoting sign language. If a State Party identifies a national sign language then it is this language that should be the focus of their development, recognition and promotion of sign language'.

Recommendation 17

That the inclusion of a specific provision on the privacy of health and other personal records be accepted, but Article 22(2) be further amended to recognise the particular sensitivity of health records for persons with disabilities.

Recommendation 18

That the words 'national laws, customs and traditions of general application' be deleted from Article 23(1)(a).

Recommendation 19

That Article 24(1) be amended to remove the words 'an inclusive education at all levels and life-long learning, directed to' and replace them with 'that education at all levels and life-long learning, is directed to'.

Recommendation 20

That Article 24(2) be amended to separate clause (d) into two clauses dealing with (a) the right to reasonable accommodation in mainstream education; and (b) the right to support from the States Parties outside the mainstream education system aimed at moving towards full inclusion in mainstream education. The NACLC proposes the following words:

Where the States Party is unable, through the provision of reasonable accommodation, to achieve substantive equality for a person with a disability in a mainstream education setting, the States Party is obliged to ensure that effective alternative support measures are provided that are aimed at effective education and achieving full inclusion in mainstream education.

Recommendation 21

That Article 24(3) be amended to add a specific obligation to ensure reasonable accommodation in respect to the broader aspects of education such as life and social development skills.

Recommendation 22

That wherever reference is made to domestic law, that reference is also made to the requirement such law to be consistent with the principles set out in Article 3 and with international human rights law and jurisprudence.

Recommendation 23

That official commentaries (travaux préparatoires) or guidelines be developed internationally to support the implementation of the Convention.

1. Article 2 - Definitions

The Draft Convention currently contains a number of definitions within Article 2. While the NACLCL understands that these are not to be the subject of debate in the January meetings of the Ad Hoc Committee, it provides the following comments for consideration.

1.1 Definition of Disability

In his open letter enclosing the Chair's Text (**the covering letter**), His Excellency, Ambassador Don Mackay comments:

Views are divided as to whether it is necessary to define 'Disability' and 'Persons with disabilities'. I tend to think that we don't, as this will be very difficult, and there is the risk that we will unintentionally exclude someone.¹

At the Experts' Seminar held on 28 November 2005², His Excellency indicated that his understanding is that it is unnecessary to define disability if one considers the purpose of the Draft Convention being about achieving equality rights and the substantive provisions that provide for equality rights across a range of life activities apply to disability and so have a universal application.

Without a definition of disability this analysis can only ever operate effectively to achieve formal equality. For example, if everyone has the right to choose where they live, equal enjoyment of this right can be achieved in a formal equality sense without a State Party having to do anything. However, to achieve substantive equality where accommodations are required for the enjoyment of this right it is necessary to clarify to whom the States Parties owe the reasonable accommodation obligation.

The absence of a definition leaves the way open for three possible situations developing: that States Parties adopt their own understanding of the term, or that States Parties adopt an existing international understanding, such as is found in the World Health Organisation's International Classification of Function (**ICF**), or that they rely on the widely advocated and accepted social model.

The NACLCL considers issues in relation to these three situations below.

Whilst recognising the challenges involved in negotiating an acceptable definition, NACLCL submits that, in addition to the above discussion, it is vital that disability be defined for the following reasons.

(a) States Parties adopt their own domestic understanding

Firstly, the absence of a definition allows States Parties the potential to significantly reduce their obligations under the Draft Convention once adopted (**the Convention**)

¹ Open Letter from His Excellency, Ambassador Don MacKay, to the Ad Hoc Committee, 7 October 2005, 5.

² This Experts' Seminar was held by the Disability Studies and Research Institute and the Australian Centre for Human Rights in Sydney and titled 'Critical issues in disability and human rights: An expert appraisal of the Chair's text for a Comprehensive and integral international convention on the rights and dignity of persons with disabilities'.

by applying restrictive definitions that may exclude, for example, those that experience mental illnesses or learning disorders. This would effectively mean that rather than having a single international convention, with NACLC would have a number of national conventions that reflect shared concerns and individuals in some States would gain protection while those in other States would not. This reflects the current situation where domestic laws provide differential coverage of rights between States. A simple illustration would be that someone with a visual impairment that falls short of total blindness may be considered to be a person with disability in one State but excluded from the protection of the Convention in another.

Second, the absence of a definition also compromises the ability of the Convention to establish uniform international application. In the event that an enforcement mechanism is incorporated in the Convention, that mechanism would rely on a common understanding of the people to be protected to achieve universal application. The development of a coherent international jurisprudence around the Convention would be seriously hampered if the core concept underpinning rights is not commonly understood. The absence of a definition could well result in much of the jurisprudence revolving around the question of who is a person with a disability.

The existence of varying definitions creates a situation whereby the operation of the Convention in one State could be significantly different to its operation in another. This would create serious difficulties in the effective monitoring and enforcement of the Convention, as different States Parties could claim different obligations depending on the scope of their definition and report against that set of obligations rather than a commonly agreed set. Comparability of State implementation goes to the very heart of the achievement internationally of equality rights for persons with disabilities.

Following this observation it is also notable that the absence of a definition could present a deterrent for States considering ratification of the Convention. Without a definition, the obligations and to whom the State owes those obligations are rendered ambiguous. Without a clear articulation of what rights and obligations the Draft Convention creates and to whom they apply, States will be reluctant to participate.

The existence of a Convention that allows for differential interpretation could also undermine the willingness of States to engage at the international treaty level. If States form the view that some States Parties, through a narrower interpretation of disability, are avoiding obligations that other States Parties have willingly adopted, this will exacerbate any sense that a common set of rules is not being applied.

(b) An existing international definition

In respect of the potential for States to fall back on an internationally recognised interpretation, the one that is available is the ICF. The ICF is not a simple form of words that stands alone. Rather, it is a framework by which human function can be understood and can be applied within different policy contexts. It is really an extremely detailed recognition of the social model analysis (which is considered in detail below). It recognises the physiological and environmental (in a very broad sense) elements and the consequential impacts of the interaction of these elements.

The purpose of the ICF is not to assist in the identification of persons with disabilities, but rather in achieving understanding of the impact of social policies on people with

impairments. It doesn't provide a simple checklist of who is and who isn't a person with a disability in international law.

(c) The social model

The social model of disability is a theoretical concept used by disability scholars to understand and analyse the oppression of people with impairments. The option of relying on the social model of disability in its entirety brings another set of problems. The social model uses the following three-tiered analysis:

Impairment: Any loss or abnormality of psychological, or anatomical structure or function.

Disability: Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap: A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal, depending on age, sex, social and cultural factors, for that individual.

Handicap is therefore a function of the relationship between disabled persons and their environment. It occurs when they encounter cultural, physical or social barriers, which prevent their access to the various systems of society that are available to other citizens. Thus, handicap is the loss or limitation of opportunities to take part in the life of the community on an equal level with others.³

To fully understand and apply the social model you need to include the 'handicapping' impact of the interaction between impairment and the consequential disability, and social and environmental factors.

The definitions proposed to the Ad Hoc Committee by a number of States include all three elements of the model. For example, South Africa has proposed the following form of words:

'Disability' is the **loss or elimination of opportunities to take part in the life of the community**; equitably with others that is encountered by persons having physical, sensory, psychological, developmental, learning, neurological or other impairments, which may be permanent, temporary or episodic in nature, *thereby causing activity limitations and participation restriction within the mainstream society*. These barriers may be due to economic, physical, social, attitudinal and/or cultural factors.⁴ [Emphasis added to highlight the '**handicap**' element of the social model, and the '*disability*' element.]

³ UN Decade of Disabled Persons 1983-92 (1983) *World Programme of Action Concerning Disabled Persons*, cited in Deborah Kaplan, *The Definition of Disability* (2005) The Centre for an Accessible Society <<http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm>> at 27 November 2005.

⁴ This definition is reported by United Nations Enable from the Fourth session of the Ad Hoc Committee of 23 August 2004 <<http://www.un.org/esa/socdev/enable/rights/ahc4sumart03.htm>> at 27 November 2005. And in the materials provided from the Fourth session at <<http://www.un.org/esa/socdev/enable/rights/ahcstata3tscompilation.htm>> at 27 November 2005.

In the absence of a definition of disability, States could adopt the existence of a handicap as a prerequisite to being entitled protection under the Convention. This is problematic for two reasons.

Firstly, this approach could be used to exclude people who have impairments who, because of their particular circumstances, do not face limited opportunities as a result of limited human function. As such, it has the potential to be more exclusive than the ‘impairment and disability’ model found in the DDA. In effect, the ‘handicap’ element adds a filter of exclusion.

Secondly, by grounding the notion of handicap in the existence of barriers, this approach has the potential to provide a somewhat circular analysis. If a person has an impairment that creates functional limits, but faces no barriers to community participation (and so no ‘handicap’) then actions necessary to achieve substantive equality may well be the same as those necessary to provide formal equality.

If a person has an impairment that creates functional limits and they face barriers to community participation, then it is likely that different actions will be needed in order to achieve substantive equality, at least in some areas of life. The existence of a ‘handicap’ is premised on there being barriers created by society, barriers that would have to be removed by a State Party in order to comply with its obligations under Draft Convention. Once those barriers are removed it would be arguable, under a full social model definition, that the State Party has no further or special obligations to people with disabilities under the Convention.

The purpose of the Draft Convention is, in part, to establish that State Parties have obligations in respect of the achievement of equality rights for persons with disabilities. Those obligations may include the obligation to do something, that is, to provide reasonable accommodation. That obligation must hang off the social model concept of ‘disability’ rather than ‘handicap’ as the whole purpose of the obligation is to remove the barriers created by social and environmental factors.

The purpose of a Convention is to ensure that people with impairments have rights recognised at an international level on an equal basis to all other persons and that the particular effects of the interface of disability and the way in which societies operate are, to the maximum extent possible, ameliorated through requiring appropriate systems of support in all aspects of community life.

In light of the above comments it is important that an inclusive definition be included in order to ensure that the Draft Convention can operate effectively within the international context.

The NACLC proposes a definition that is based on the *Disability Discrimination Act 1992* (Cth) (**the DDA**). The NACLC recognises that the purpose and context of this definition in the DDA requires it to be modified to accord with the purpose of the Draft Convention.

The NACLC’s preferred definition is:

Disability includes:

- (a) total or partial loss of the person's bodily or mental functions, or
- (b) total or partial loss of a part of the body, or
- (c) the presence in the body of organisms causing disease or illness, or
- (d) the presence in the body of organisms capable of causing disease or illness, or
- (e) the malfunction, malformation or disfigurement of a part of the person's body, or
- (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction, or
- (g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgement or that results in disturbed behaviour,

This definition draws on both concepts of impairment and disability from the social model. It potentially broadens the scope of the definition from the DDA by using the term 'includes' rather than 'means'. One of the significant benefits of this definition is it does not rely on the labels of physical, sensory, psychological that are commonly found in domestic anti-discrimination laws. It is also generally the case that any particular disability is likely to fit within more than one of the categories listed. This expands its potential to be inclusive.

While it is our view that the definition of disability ought not include concepts of past, future, or imputed disabilities, the NACLC recognises the need to ensure that the provisions dealing with non-discrimination include these concepts. As such, it is necessary to include past, future and imputed disabilities in the definition of discrimination on the basis of disability in Article 2.

If a person is excluded from the enjoyment of rights on the basis of a past, future or imputed disability they require and deserve protection regardless of if they actually experience that disability or not. They also need to have recourse to remedial mechanism under anti-discrimination laws at a domestic level.

Recommendation 1

That the position that no definition of disability is required in the Convention be revised and replaced with an inclusive definition of disability that relies on the 'impairment' and 'disability' elements of the social model and reflects the definition in the *Disability Discrimination Act 1992*.

Recommendation 2

That the definition of 'discrimination on the basis of disability' in Article 2 be amended to include distinctions, exclusions or restrictions on the basis of past, future or imputed disabilities as well as current.

1.2 Definition of Reasonable Accommodation

The current definition of 'reasonable accommodation' is 'appropriate modification and adjustments not imposing a *disproportionate burden* ...'

The NACLC notes that this is a significant shift in interpretation from that usually applied in those jurisdictions that have a robust and well-established jurisprudence around ‘reasonable accommodation’ (or its equivalents). It is a shift in two regards.

Despite recent developments in Australia, the notion of ‘reasonable accommodation’ does not usually import a limit on the obligation. A reasonable accommodation is any change in the situation that enables a person with a disability to enjoy equal opportunity in the relevant circumstance. It is most commonly understood in the context of employment, where the accommodation may be a change to the work environment or to the way in which the job is to be done.

The usual obligation is for the provider or employer to provide reasonable accommodations unless to do so would be to impose an unjustifiable or undue hardship.

The NACLC submits that this two-pronged analysis is clearer and a more appropriate way to consider the question of both the ‘reasonableness’ of the accommodation and the limits imposed on it. The question of reasonableness needs to have international application and this can only be achieved if it does not import capacity to bear the cost of the accommodation. Rather, it should remain restricted to the question of what is needed to enable the person to enjoy substantive equality.

Further, the NACLC of the opinion that ‘disproportionate burden’ is an unsatisfactory standard to use to limit the obligation to make reasonable accommodation. It is unsatisfactory because it is highly subjective, it does not require any significant measure of difference the usual effort involved in an action and the additional effort requirement to afford substantive equality, it uses a term already used in equality law in notions of indirect discrimination and the disproportionate effect of an otherwise neutral term or condition (where the understanding is that any statistically significant effect is sufficient), and that it provides no basis by which to test a State’s assessment that modifications and adjustments were a ‘disproportionate burden’.

This language and construct of reasonable accommodation reflects that found in Article 5 of the European Community’s *Employment Equality Directive*.

In order to guarantee compliance with the principle of equal treatment in relation to persons with disabilities, reasonable accommodation shall be provided. This means that employers shall take appropriate measures, where needed in a particular case, to enable a person with a disability to have access to, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on the employer. This burden shall not be disproportionate when it is sufficiently remedied by measures existing within the framework of the disability policy of the Member State concerned.⁵

It is important to note that Article 5 itself includes an interpretive aid in the final sentence and the language in Article is supported by an interpretive provision in paragraph (21) of the Preamble:

⁵ Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation [2000] OJ L 303/16, 19.

To determine whether the measures in question give rise to a disproportionate burden, account should be taken in particular of the financial and other costs entailed, the scale and financial resources of the organisation or undertaking and the possibility of obtaining public funding or any other assistance.⁶

The NACLC notes that there is no jurisprudence around Article 5.

In all the circumstances, the NACLC advocates for the use of ‘unjustifiable hardship’ as the standard at which a limit applies to the obligation to provide reasonable accommodation on the basis that it places a higher onus on the States Parties to demonstrate why a failure to accommodate was not practically possible. It will also require a more comprehensive consideration of the ability of the State to make the adjustments, the costs and disadvantages of those adjustments to the State, and the benefits of those adjustments to individuals involved.

Recommendation 3

That the current the definition of ‘reasonable accommodation’ in Article 2 be replaced with the following language:

‘Reasonable accommodation’ means necessary and appropriate modifications and adjustments needed, in a particular case, to ensure to persons with disabilities the enjoyment or exercise on a basis of equality with others of all human rights and fundamental freedoms including those set out in this Convention.

Recommendation 4

That the Draft Convention be amended to include, wherever there is an obligation to reasonably accommodate, that the limit on that obligation is based on the principle of unjustifiable hardship.

⁶ *Ibid*, 17.

2. Specific Population Groups

2.1 Interpretative Article

The NACLCLC notes the considerable debate around the issue of inclusion of specific population groups in the Draft Convention. The NACLCLC is of the opinion that it is essential that the Draft Convention include acknowledgement of the impacts of disability on persons of specific population groups, of which women and children are two examples, who may experience a compounding disadvantage.

The NACLCLC endorses the approach recommended in the *Report on National Consultations on the Comprehensive and Integral International Convention on the Rights and Dignity of Persons with Disabilities*⁷, that a general interpretative article be included to recognise the intersection of disability with particular personal characteristics or special circumstances including:

- women with disability;
- children and young people with disability;
- Indigenous people with disability;
- elderly persons with disability;
- people with severe and/or multiple disabilities;
- people with disability from racial, ethnic, linguistic and/or religious minority groups;
- sexual orientation;
- people in situations of war or internal conflict; and
- people living in rural, remote and small island communities.

Furthermore, where States Parties are required to report against the substantive provisions in Part II, it should be clear that reference will need to be made as to how any action taken under these articles deals with unique needs of these specific groups.

Recommendation 5

That the Draft Convention include a general interpretative article recognising the impact that results from the intersection of disability with particular personal characteristics or special circumstances.

2.2 Inclusion of separate articles on specific population groups

Should the majority of States parties not accept the interpretative article proposed at 2.1 above, the NACLCLC recommends the inclusion of separate articles identifying the particular disadvantages experienced by women children with Indigenous people with disabilities and of people with disabilities from racial, religious and ethnic minorities. The articles should specify that they operate to provide an interpretive element to

⁷ People with Disability Australia Inc, Australian Federation of Disability Organisations, National Association of Community Legal Centres (2004) *Report on National Consultations on the Comprehensive and Integral International Convention on the Rights and Dignity of Persons with Disabilities*, 22.

other articles in the Draft Convention. These articles would operate to draw States Parties' attention to how measures may need to be taken to address the unique needs of these groups in realising the rights that exist within the Convention *as a whole*.

Furthermore, where States Parties are required to report against the substantive provisions in Part II, it should be clear that reference will need to be made as to how any action taken under these articles deals with the unique needs of these specific groups.

Recommendation 6

That in the alternative to Recommendation 5 that the Draft Convention incorporate specific articles aimed at the particular disadvantage of women, children and Indigenous people with disabilities, and of people with disabilities from racial, ethnic or religious minorities.

3. Article 12 - Equal recognition as a person before the law

This Article deals with concepts at the core of the rights of people with disabilities as human beings and the exercise of those rights. It is vital that this Article be clear in its intended scope and meaning and provides clear guidance to States Parties on the circumstances in which support or intervention may be permissible and on the appropriate safeguards for such support or intervention.

This is, in our view, an article that needs to be right; it is not enough to ask the question ‘can we live with it?’

3.1 Distinguishing between legal capacity and the exercise of that capacity

In the covering letter, the Chair asks delegations to specifically consider this Article in order to appropriately resolve how to distinguish between the legal capacity of all persons and the exercise of that capacity, which may require some assistance in certain circumstances.

The NACLC is of the opinion that the Article in its current form achieves this objective.

Article 12(1) sets forth the fundamental principle that people with disability have a right to recognition as persons before the law.

Article 12(2) is narrower, and relates to one aspect of recognition before the law: legal capacity. It recognises that all persons have legal capacity, however that there may be circumstances in which a person’s disability prevents them from exercising legal capacity, due to an inability to engage with or understand the legal process. This provision then provides, in sub-paragraph (a), the obligation to ensure that all attempts are made to support and encourage the participation of any individual in the exercise of their legal capacity and provides for procedural safeguards in this process. It provides, in sub-paragraph (b), a mechanism more specifically for substituted decision making with procedural safeguards.

In effect, Article 12(2) provides guidance on the way in which accommodations are to be implemented with respect to the exercise of legal capacity. This is not a circumstance where there should be any limit on the duty to provide reasonable accommodation.

Therefore Article 12(2) does not detract from the fundamental principle that a person has a right to recognition under the law, but instead establishes safeguards to prevent derogation from that recognition in the event that a person is unable to fully exercise their legal capacity.

3.2 Supported and substitute decision making

The NACLC understands Article 12(2)(a) as a reference to supported decision-making in situations where a person's disability inhibits their ability to exercise their legal capacity. The NACLC suggests that the Article would benefit from explicitly referencing supported decision-making. Consideration could also be given to noting that the matters to be considered are not simply the degree of support but also the nature of the support required. The Article is unclear in the intended meaning of and obligations arising from 'respects the will and preferences of the person'. This could be understood to mean to have regard to the person's views, but not to be bound by them, or to mean to have regard to and be bound by those views. While formal mechanisms such as advance directives and enduring wills provide one mechanism for persons with disabilities to bind others to their will and preference into the future, these do not cover the field as they rely on capacity at the time of making.

It is important to consider the continuum of support that may be provided to a person in a decision-making process. Many people with disabilities have advocates who assist them in decision making through ensuring that the person with a disability has the information available to them to understand, to the extent possible, the decision to be made and the potential impacts of that decision. Another role of advocates is to ensure that the views and wishes of the person with a disability are being heard when decision-making has been taken out of their hands. Their role is not to become the decision maker but may be seen as verging on a supportive decision-making role.

Along the continuum is a person in a supportive decision-making role, who should, to the extent possible, be bound by the person's will but where there are significant risks and the person is unable to demonstrate an understanding of those risks, they should base their decisions on the person's best interests. To some extent, this area of the continuum may well be best focussed on those areas of decision making that are day to day and likely to have limited long-term and serious impact on the person's life.

Finally, the substitute decision maker is empowered to make the decisions in the best interests of the person with a disability. While they may have regard to the views of the person, they are not bound by those views.

Ideally, for the conceptual consistency of the Convention, Article 12(2) should expressly refer to an unlimited duty to reasonably accommodate and 12(2)(a) should merely set out the procedural safeguards where support is provided to a person with a disability in their exercise of legal capacity. Further, there are concerns about the ability to achieve effective support for decision-making that is free from conflict of interest. At least in some areas of life, the support will come from family members and friends. These people may well be the most appropriate to give the support but clearly have an interest that may, at time, be different from that of the person with the disability.

The NACLC notes the inclusion of the qualification 'Where appropriate' in Article 12(2)(a). Presumably it is included to cover situations where a person's disability is perceived to permanently inhibit their ability to exercise legal capacity. The NACLC submits that regardless of this perception of permanence, where the exercise of legal capacity is either supported or substituted, independent review is vital to ensure the exercise of the right to capacity is genuinely respected, supported and monitored.

The NACLC understands Article 12(2)(b) as a reference to substituted decision-making. Given that there will be circumstances where substituted decision-making powers may be required, the NACLC believes it is *essential* that the protective provisions that are expressed in Article 12(2)(b) be retained. The importance of a competent, impartial and independent tribunal to assess the appointment and decisions of a substituted decision-maker cannot be overstated. It may be useful to make it clear that ‘last resort’ should encompass the existence of credible evidence of incapacity and a current need for a substitute decision maker to be appointed. The NACLC also suggests that this provision would benefit from explicitly referencing the term ‘substituted decision making’.

An option for reframing Article 12(2) is to set out the obligation to provide reasonable accommodation in the head paragraph of the article, and to set out the principles to guide both supported and substitute decision making in one sub-paragraph, and the principles to govern appointment, monitoring and review of supported and substituted decision making in a second sub-paragraph.

Recommendation 7

That Article 12(2) be amended to ensure the express recognition of the right to reasonable accommodation in the exercise of legal capacity.

Recommendation 8

That the text ‘[legal capacity]’ be included in Article 12(2) and the words ‘the capacity to act’ be deleted with ‘that capacity’ retained.

Recommendation 9

That the terms ‘supported decision making’ and ‘substituted decision making’ be used in Article 12(2).

Recommendation 10

That serious consideration be given to restructure of Article 12(2) to set out the obligation to provide reasonable accommodation for the exercise of legal capacity in the head paragraph of the article, and to set out the principles to guide both supported and substitute decision making in one sub-paragraph, and the principles to govern appointment, monitoring and review of supported and substituted decision making in a second sub-paragraph.

4. Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment

Article 15(1) emphasises the importance of informed consent in the participation of medical and scientific experimentation. However, it should be recognised that participation in medical trials may be beneficial to the person concerned in situations where they personally are unable to consent. In these situations, informed consent should be available through substituted or supported decision making. However, there should be some mechanism for independent oversight prior to approval being given. The NACLC notes that in the Australian state of New South Wales (NSW) the mechanism to enable participation in clinical trials is for a tribunal to review the trial and, if approval is given to the trial, then the substitute decision maker may consent to the person's participation.⁸

The NACLC recommends that the Draft Convention include an interpretive article that defines consent to include the consent available through substituted or supported decision making under Article 12.

Recommendation 11

That an interpretive Article that defines consent to include the consent available through substituted or supported decision-making be included in the Draft Convention.

Recommendation 12

That the option of participating in clinical trials with consent and with prior approval of the trial or equivalent by an independent judicial or quasi-judicial decision-making body be included.

⁸ See Part 5, Division 4A of the *Guardianship Act 1987* (NSW), ss 45AA and 45 AB.

5. Article 17 - Protecting the integrity of the person

Article 17 has special significance for people with disability who are often the subject of compulsory treatment programs. It is appropriate that this Article be included provide protection in the instance that a person can be the subject of involuntary treatment.

The NACLC notes a degree of inconsistency in the language between paragraphs 17(2) ('forced interventions or forced institutionalisation'), 17(3) ('involuntary treatment'), and 17(4) ('involuntary treatment'). The NACLC also notes this language is inconsistent with Article 15, which refers to consent. The NACLC recommends that the language relating to consent be made consistent throughout.

Given the serious nature of any intervention where the integrity of the person is in question, it is our view that even with consent there should be safeguards around non-emergency interventions or treatment.

Paragraph 17(2) should clearly refer to interventions or institutionalisation solely aimed at correcting, improving or alleviating any actual or perceived disability. Regardless of the mechanism by which consent to such interventions or institutionalisation is achieved, no action of this sort should be permissible without a process of independent review that is established by law consistent with the Convention and international human rights law.

The Article should make it clear that all other interventions that impact on the integrity of the person should only be undertaken when the usual consent requirements have been fulfilled. For example, if no consent is required to undertake an emergency medical procedure, then no consent ought be required where a person with a disability requires such a procedure.

The NACLC submits that it is vital that 17(4) be included but modified to take account of treatment or interventions *with or without consent*. In light of our comments above in respect of paragraph 17(2), the list of safeguards included in Article 17(4) can be reduced to remove sub-paragraph (b). The remaining principles are appropriate in respect of any form of intervention that impacts on the integrity of the person.

Finally, for consistency throughout, the language used should be interventions or institutionalisation rather than treatment. The Draft Convention generally should be reviewed to ensure consistency of this language.

Recommendation 13

That Article 17 be amended to remove the use of the terms 'involuntary' and 'forced', and for the Article to be redrafted to the extent necessary to use the term 'without consent'.

Recommendation 14

That a new paragraph be included in Article 17 to provide safeguards to ensure that any intervention contemplated within paragraph 17(2) with consent be subject to a requirement that it be approved by an independent court or tribunal in accordance with law, with the application of appropriate legal safeguards and consistent with the Convention and international human rights law.

Recommendation 15

That Article 17(4) be modified to refer to any form of intervention (whether it be with consent or without), and that sub-paragraph (b) of Article 17(4) be removed but all of the remaining safeguards be retained.

6. Article 21 - Freedom of expression and opinion, and access to information

The NACLC notes that not all States have a formally acknowledged national sign language, and accordingly Article 21(e) may not be achievable.

Recommendation 16

That Article 21(e) be amended to read 'developing, recognising, promoting sign language. If a State Party identifies a national sign language then it is this language that should be the focus of their development, recognition and promotion of sign language'.

7. Article 22 - Health information privacy

The NACLC commends the Chair on his inclusion in Article 22 the second paragraph obliging States Parties to protect the privacy of personal, health and rehabilitation information about persons with disabilities.

The NACLC notes that Australian privacy laws recognise the particular sensitivity of health and related information and suggest that the Draft Convention could be enhanced through the addition of text that similarly requires that sensitivity to be recognised. This is particularly the case when considering the increased potential for the release of health information to have significant negative consequences where the person concerned is a person with a disability.

Recommendation 17

That the inclusion of a specific provision on the privacy of health and other personal records be accepted, but Article 22(2) be further amended to recognise the particular sensitivity of health records for persons with disabilities.

8. Article 23 - Respect for the home and family

The NACLCLC is concerned by the proposed inclusion of ‘national laws, customs and traditions of general application’ in Article 23(1)(a). Whilst acknowledging the concerns identified in the covering letter with respect to different cultural approaches to sexuality, the inclusion of such subjective elements of ‘national laws, customs and traditions’ permits States Parties to discriminate, directly or indirectly against people with disabilities.

The intent of the inclusion of this phrase is essentially already achieved through the operation of chapeau in Article 23(1)—on an equal basis with others—which would subsume any laws of genuine ‘general application’ but not permit any laws, customs or traditions which have the effect of discriminating against people with disability.

Recommendation 18

That the words ‘national laws, customs and traditions of general application’ be deleted from Article 23(1)(a).

9. Article 24 - Right to education

The NACLC commends the Ad Hoc Committee on the work done in the difficult area of the right to education in the context of disability.

The NACLC understands that the five paragraphs of the article effectively seek to cover/articulate the following principles:

1. The fundamental right to education and the meaning and purpose of education.
2. That there be a presumption that people with disabilities will have a right to be educated in mainstream educational settings.
3. That persons with disabilities have a right to the specified reasonable accommodations in education to achieve life and social development skills aimed at full and equal participation in education and the community
4. That States Parties are obliged to provide people with sensory disabilities with education facilitated by teachers appropriately skilled in key communication modes.
5. That people with disabilities have a right to substantive equality rights in all forms of post-secondary education.

The NACLC further understands that there is an underlying tension between the general push for fully inclusive education and the specific advocacy by the Deaf, blind and deaf-blind communities for a right to segregated or congregate education settings, that is a right for a person with a sensory disability to be educated alongside others with the same disability.

The key question to be considered is whether or not the Article as currently drafted achieves the aim of ensuring that people with disabilities have real and effective right to education and to a real and effective choice about their education setting.

The NACLC is concerned to ensure that any segregated (or congregate) education right does not preclude people with sensory disabilities being educated within the same educational setting as other members of their family and neighbourhood. A risk of a fully congregate right is to prevent a child who is hearing from being educated with her or his deaf sibling and not having the same access to sign language development.

9.1 Paragraph 1

Given the clear statements in paragraph 2 about inclusion in the general education system, it is not, in our view, necessary or appropriate to qualify the obligation on States Parties to ensure education at all levels, etc, with the term 'inclusive'. Rather, the purpose of paragraph 1 should be to set out the principle of the right to formal and substantive equality in all aspects of education.

Recommendation 19

That Article 24(1) be amended to remove the words 'an inclusive education at all levels and life-long learning, directed to' and replace them with 'that education at all levels and life-long learning, is directed to'.

9.2 Paragraph 2

The only concern with this paragraph is the conflating of two key principles in clause (d). The first sentence of that clause deals with the right to reasonable accommodation to achieve substantive equality for persons with disabilities in mainstream education. The second sentence deals with what should occur where a person is excluded from mainstream education. These, in our view, should be dealt with in separate clauses. (The NACLC notes that clause (c) deals with the provision of reasonable accommodation and, to that extent, the first sentence of (d) is somewhat repetitive.)

The NACLC understands that the latter principle is about segregated education as a last resort, particular in relation to persons with other than sensory disabilities. If this is a correct analysis, the NACLC is concerned to ensure that the sense that last resort or ‘exceptional circumstances’ means ‘after all possible reasonable accommodations’ have been considered or implemented.

Recommendation 20

That Article 24(2) be amended to separate clause (d) into two clauses dealing with (a) the right to reasonable accommodation in mainstream education; and (b) the right to support from the States Parties outside the mainstream education system aimed at moving towards full inclusion in mainstream education. The NACLC proposes the following words:

‘Where the States Party is unable, through the provision of reasonable accommodation, to achieve substantive equality for a person with a disability in a mainstream education setting, the States Party is obliged to ensure that effective alternative support measures are provided that are aimed at effective education and achieving full inclusion in mainstream education.’

9.3 Paragraph 3

To the extent that paragraph 24(3) deals with a right to be provided with appropriate facilitation for the development of reading, language and communication and with assistance to develop the skills and knowledge necessary to effectively participate in the life of the school and community, this should be seen as reflective of the broader obligation to provide reasonable accommodation in education. As such a further clause should be added to expressly observe that States Parties should provide reasonable accommodation to achieve the aim of enabling persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education.

One issue that does arise is whether or not this is the proper place for the Draft Convention to deal with a right to culture and the development and sustaining of culture. While the NACLC acknowledges that educational settings play an important part in cultural maintenance and development, they tend to do this as an inevitable by-product of the congregation of members of a community. To the extent that paragraph 24(3)(b) deals with the promotion of linguistic identity the NACLC suggests consideration be given to redrafting, with this aspect located more properly in Article 30.

A key aim of this paragraph should, in our view, be to facilitate a broader engagement with and understanding of the culture (and language) of specific communities of persons with disabilities. This is more likely to be achieved if States Parties focus on providing appropriate language and communications support within mainstream settings that encourage not only students with disabilities accessing that support, but also other members of the education community.

Recommendation 21

That Article 24(3) be amended to add a specific obligation to ensure reasonable accommodation in respect to the broader aspects of education such as life and social development skills.

10. Other comments

There are a number of places in the Draft Convention that provide for actions ‘subject to law’ or ‘established by law’. At some points, these are qualified by the requirement that the laws must be consistent with the Convention and with international human rights law.

The NACLC submits that this qualification should be used throughout.

Recommendation 22

That wherever reference is made to domestic law that reference is also made to the requirement that such law be consistent with the principles set out in Article 3 and with international human rights law and jurisprudence.

Many of the concepts the NACLC is exploring in the discussion set out in this submission could, the NACLC submits, be usefully included in a commentary to the Convention. Many of these issues are new or emerging and will not be within the familiar domain of those responsible for implementing the Convention at either an international or domestic level.

Recommendation 23

That official commentaries (travaux préparatoires) or guidelines be developed internationally to support the implementation of the Convention.

Finally, the NACLC notes that the Draft Convention provides no comment in respect of the potential impact of reduced legal capacity on responsibility for actions in a legal sense. The NACLC understands that this is a somewhat controversial issue at the UN. The NACLC is concerned that there be a mechanism whereby a court is required to take account of the disability or its impact where a person commits an offence when they didn’t have the legal capacity to understand either the consequences of their action or the unlawfulness of it.