

Year 5 • Number 8
June 2008

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Access to medicines and intellectual property in Brazil: reflections and strategies of civil society



HUMAN RIGHTS
UNIVERSITY NETWORK

SUR

A project of Conectas Human Rights

SUR - INTERNATIONAL JOURNAL ON HUMAN RIGHTS is a biannual journal published in English, Portuguese and Spanish by Sur - Human Rights University Network. It is available on the Internet at <<http://www.surjournal.org>>

SUR - International Journal on Human Rights is listed in the *International Bibliography of the Social Sciences* (IBSS).

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Pro! Editora Gráfica Ltda.

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SUR - HUMAN RIGHTS UNIVERSITY NETWORK is a network of academics working together with the mission to strengthen the voice of universities in the South on human rights and social justice, and to create stronger cooperation between them, civil society organizations and the United Nations. Conectas Human Rights, a not-for-profit organization founded in Brazil, is home to Sur. (See website <www.conectas.org> and portal <www.conectasur.org>. To access the online version of the journal, please go to: <www.surjournal.org>.)

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The financial assistance of the Ford Foundation, the United Nations Democracy Fund and the United Nations are gratefully acknowledged.

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PRESENTATION



With the aim of seeking out different perspectives and dealing with subjects of a specialized nature, Conectas Human Rights has been creating partnerships with non-governmental human rights organizations in diverse parts of the world. In this issue of *Sur – International Human Rights Journal*, which is principally focused on access to medicines, a new cooperative partnership was formed with the Brazilian Interdisciplinary AIDS Association – ABIA.

Founded in 1987, it is the mission of ABIA to promote access to treatment and assistance to persons living with HIV and AIDS. Along these lines, ABIA has been monitoring public policies and developing projects regarding education, prevention, and access to information about HIV/AIDS. ABIA has also been coordinating the Working Group on Intellectual Property of the Brazilian Network for the Integration of Peoples – GTPI – REBRIP, in order to enrich and enlarge the debate over the harmful impacts of the rigid rules regarding intellectual property in the area of access to essential medicines, in addition to contributing to the construction of alternatives to the present model.

This eighth issue of the *Sur Journal* is divided into two parts: the first specifically examines access to medicines, while the second deals with questions that evaluate the present state of human rights in general.

Beginning with the discussion over access to medicines, the main problems related to the often conflicting interaction between human rights and international trade are debated. Those questions deal with the conflict between the human right to health and the protection of pharmaceutical innovations; efforts at making businesses responsible and breaking away from the protective framework initially confined to the sphere of the State; and the developing of the public debate over the political use of judicial power.

In the article by Chaves, Vieira and Reis the system for the protection of intellectual property is discussed, taking as a starting point the situation in Brazil. The relevance of the Brazilian case is based on Brazil's adoption of a policy of universal access to medicines for the treatment of AIDS as well as its recent adoption of a compulsory license for the supply of antiretroviral medicines. The model of universal access and the adoption of a compulsory license represent important benchmarks for the recognition of the preference of human rights over economic interests. The article also presents the main action strategies adopted by a Brazilian group of activists that has had a profound effect on the area. The description of these strategies is important because it enhances the possibility of exchanging experiences with other activist groups in the South.

In the article by Pogge, the author discusses the argument that patents stimulate pharmaceutical innovation. For the author, this system strengthens monopolies and the

concentration of research on the symptoms, and not the causes, of chronic illnesses. At the same time the treatment of specific illnesses of poorer populations is relegated to a secondary position because it is less profitable, thus increasing the rate of avoidable deaths. The author goes beyond simply spelling out the problem. He presents a proposal that would complement the patent system: a Health Impact Fund, financed by governments. This Fund would stimulate the development of new medicines with the promise of re-compensating successful innovators in proportion to the impact of the medicine on the global burden of illness.

The article by Hunt and Khosla deals with the responsibility of pharmaceutical businesses, along with the presentation of normative guidelines for health rights. In this sense, the article written by the Rapporteur of the United Nations on the right to health could be interpreted almost as “soft law”, assisting in the structuring of this right in regard to the access to medicines.

In the last article of this first part of the Journal, which was authored by Contesse and Lovera, the question of access to medicines is analyzed beginning with individual cases that depict the perspective of those that lack access to medicines in Chile. The authors show how the litigation process can be used politically to create a public debate to sensitize the executive and legislative branches of the government to enact new public policies.

In the second part of this issue of the Sur Journal, the following issues are discussed: the justiciability of economic, social, and cultural rights (Cavallaro and Brewer); the growing consolidation of sexual rights as autonomous rights (Mattar); the participatory preparation and adoption of a new international treaty on rights of persons with disabilities (Dhanda); and the challenges that have to be overcome by non-governmental human rights organizations (Abregu).

We would like to thank the following professors and partners for their contribution in the selection of articles for this issue: Alejandro Garro, Bernardo Sorj, Carlos Correa, Denise Hiraó, Frans Viljoen, J. Paul Martin, Jeremy Julian Sarkin, Juan Amaya, Julieta Rossi, Mustapha Al-Sayyed, Richard Pierre Claude, Roberto Garretón, Roger Raupp Rios, and Vinodh Jaichand.

Finally, we would like to announce that the next edition of Sur Journal will be a special issue in commemoration of the sixtieth anniversary of the Universal Declaration of Human Rights. The next issue will be published in partnership with the *International Service for Human Rights*.



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ABSTRACT

The Article examines the Convention on the Rights of Persons with Disabilities, which is the first human rights instrument of the millennium to understand how the disability rights discourse has been altered, and to contribute to human rights jurisprudence. This is because the Convention alters the lexicon of disability rights and offers fresh insight on the way to resolve some perennial human rights dilemmas.

Original in English.

KEYWORDS

Persons with disabilities – Welfare – Discrimination – Autonomy –
Indivisibility - Participation



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CONSTRUCTING A NEW HUMAN RIGHTS LEXICON: CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Amita Dhanda

I. Introduction

The emergence of a unipolar world has resulted in traditional understandings of international law to be challenged. This challenge has included the raising of queries on the relevance of the United Nations system, which was founded on the power dynamics of the post war world. The United Nations it has been contended is not in harmony with the hopes and aspirations of the global south and operates much more like the hand maiden of the first world countries.¹ Further the human rights instruments which were a mechanism to obtain accountability from States have yielded meager benefits to the people on the ground; instead these Charters of universal values have become a convenient stick in the hand of the first world with which to batter the third world. These criticisms along with others have prompted some of the structural reform efforts that engage the attention of the World body. Amongst them being a reconstitution of the permanent members of the Security Council; and the effort to restructure and reform the treaty implementation bodies.²

It is in this environment of growing skepticism, which the reform efforts have in no way curbed, that the United Nations has adopted the Convention on the Rights of Persons with Disabilities. A new human rights convention may not arouse optimism, especially when the convention addresses the concerns of a special group as is the case with the United Nations Convention on the Rights of Persons with Disabilities (hereinafter CRPD), which was adopted by the General Assembly on the 13th of December, 2006 and was opened for

Notes to this text start on page 37.

signature by State parties on 30th March, 2007. The Convention required 20 ratifications to come into force and the last of these instruments was deposited with the UN Secretariat on 3rd of April 2008. The Convention thus came into force on the 3rd of May.³

Insofar as international human rights law goes, the process of negotiating, drafting, adopting and enforcing the CRPD has been a relatively quick one. Despite these happy developments, persons with disabilities are continually informed that their expectations from the United Nation system were naive and unreal.⁴ Studies documenting the impact of the Women's Convention⁵ and the Child Rights Convention are often mentioned in order to establish this point. As already mentioned the CRPD has just obtained the last of the ratifications that was required to bring it into force. As the CRPD is just about ready to come into force, it is neither empirically possible nor normatively desirable to assess whether or not it will change the situation of persons with disabilities on the ground. It is important to note that the CRPD is a human rights instrument and hence universal law. Though the explicit provisions of CRPD enunciate the rights of persons with disabilities; the philosophy informing these rights, as also the procedure followed for arriving at the text of the CRPD cannot be limited to disability alone. The CRPD can thus be appropriately introduced as the most recent member of the human rights family. In this capacity, it is necessary to obtain acquaintance with the CRPD not just to understand what it promises to persons with disabilities; but also to comprehend what it contributes to human rights jurisprudence. Consequently in this article I examine the CRPD in order to highlight and analytically describe what the Convention does for disability rights and how it contributes to human rights jurisprudence. Before I undertake this analysis, primarily to provide a socio-political context to the adopted text I briefly describe the developments which informed the movement for a special convention for persons with disabilities.

The present move to persuade the United Nations to adopt a human rights convention for persons with disabilities was not the first of its kind. Efforts to obtain a disability rights convention had been earlier made by Sweden and Italy but without success. The previous initiatives were turned down on the reasoning that disability was in no way excluded from general human rights instruments; consequently there was no need to adopt a special convention on disability rights. Despite these claims of normative inclusion the ground level experience of persons with disabilities was one of deprivation. These rejections in effect, invisibilized both persons with disabilities and the disability experience. As the lived experience of persons with disabilities in no way matched the reasoning used to shoot down a special convention, an effort to persuade the world body was made yet again by Mexico.

It is significant to note that even as the international community did not accede to the claims of persons with disabilities for a special convention it admitted to the ground level difficulties encountered by persons with disabilities by adopting Standard Rules on the Equalization of Opportunities for Persons with Disabilities⁶ and the World Program on Action. Prior to the adoption of these implementation supporting documents the world body also proclaimed the UN Declarations on the Rights of Mentally Retarded Persons⁷ Rights of Disabled Persons⁸ and the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental HealthCare.⁹ These soft law instruments which were adopted without the participation of persons with disabilities signify how the non disabled world perceive disabilities and hence create a lower standard of rights for persons with disabilities. It is significant that whilst the CRPD recognizes the efforts made through the World Program of Action and the Equalization Rules¹⁰ it maintains a total silence on the two Declarations and the MI principles. This silence has been maintained because persons with disabilities were highly critical of the pejorative and patronizing tone of these soft law instruments. A comparison of these instruments and the CRPD, which is not the objective of the present article, illuminates the differences between the welfare and the rights approach.¹¹ These instruments which had no binding legal force are being mentioned primarily to highlight the paradigm shift that the CRPD makes in enunciating the rights of persons with disabilities. It is to those ideational changes that we now turn.

II. What has the CRPD done for persons with disabilities?

It is my view that the CRPD has done the following for persons with disabilities: it has signaled the change from welfare to rights; introduced the equality idiom to grant both same and different to persons with disabilities; recognized autonomy with support for persons with disabilities and most importantly made disability a part of the human experience.

From welfare to rights

The CRPD is not the first international instrument that has engaged with the issue of disability. The Declarations and Equalization Rules have already been mentioned. An examination of soft law instruments and especially the Equalization Rules shows how the Rules were almost an exclusive engagement with social economic rights. Thus in the preconditions for equal participation the CRPD mentions awareness raising;¹² medical care;¹³ rehabilitation¹⁴ and support services.¹⁵ In the target areas for equal participation the Equalization

Rules refer to accessibility;¹⁶ education;¹⁷ employment;¹⁸ income maintenance and social security;¹⁹ culture;²⁰ recreation and sports;²¹ and religion.²² Except for Rule 9 which speaks of family life and personal integrity the Equalization Rules, only engaged with policy rights²³ that made good the developmental deficits faced by persons with disabilities. There was an ominous silence on civil political rights in all these instruments.

Thus no need was felt to guarantee to persons with disabilities the right to life, right to liberty and security, the freedom of speech and expression or the right to political participation. The absence of a regime of civil political rights for persons with disabilities significantly contributed to the welfarist approach because international human rights law has conferred the qualities of immediacy and justiciability to civil and political rights. Social economic rights are progressively realized subject to availability of economic resources. The gradualness of realization renders these rights constantly negotiable. The characteristics of immediate availability and justiciability contribute to the non-negotiable visage of civil and political rights, and enable the bearers of these rights to assert them without defensiveness or shame.²⁴ In the absence of a civil and political rights regime, persons with disabilities were unable to assertively claim their rights; they had to continually negotiate for the same.

The CRPD recognizes that persons with disability have right to life on an equal basis with others.²⁵ This affirmation in itself without more challenges the belief that a disabled life is a less valued life and hence it does not need to be protected. The right to life is an assertion that difference of disability contributes to richness and diversity of the human condition and is not a deficit that has to be selected out.

The value of the disability perspective is reinforced by other civil and political rights such as the right to liberty and security,²⁶ freedom of speech and expression;²⁷ physical and mental integrity.²⁸ The right to political participation is an acknowledgement that the lives of persons with disabilities cannot be organized by non-disabled others²⁹ and there is a disability dimension to every law and policy hence such laws and policies should not be finalized without the full participation of persons with disabilities.³⁰

Equality and non-discrimination

The CRPD is sworn to the objective of non-discrimination evidenced in the right to equality. However the recognition of this right has caused to surface the age old questions which surround the discourse of equality. What do persons with disability want: Do they want the same as non-disabled world or do they want different? Do all persons with disabilities want the same or do they want different? This conundrum of sameness and difference has haunted every

excluded group in its journey of inclusion. The CRPD has avoided this interminable debate by seeking both same and different. Thus whilst persons with disabilities are entitled to the same respect and dignity as the rest of the humanity;³¹ they are also entitled to reasonable accommodation³² of their difference in order to obtain the outcome of inclusion and full participation.³³

The issue of sameness and difference is not only relevant in the context of the disabled and the non-disabled world. It holds as much significance whilst determining the relationship between different segments of the disabled world for example how should the question of inclusion in education be addressed, when there are disadvantages in ghettoizing persons with disabilities in special schools and yet there are special skills that persons with disabilities need to learn for their own capability development. The convention has once again not opted for an either or choice but has chosen to allow both same and different. Thus for example article 24(3) requires states parties to “enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community”. And 24 (3) (c) then requires states parties to ensure “that the education of persons and in particular children who are blind, deaf or deafblind is delivered in the most appropriate languages and modes and means of communication for the individual and in environments which maximize academic and social development”.³⁴

Autonomy and support

The third issue on which the CRPD significantly contributes in altering the accent of the rights of persons with disabilities is the issue of autonomy and support. An examination of the legal systems across the world shows that if there is one body of persons who has not been recognized as people who have the ability or capacity to be able to manage their own lives – it is persons with intellectual and psychosocial disabilities.³⁵ This belief in the incapacity of persons with psychosocial and intellectual disabilities has been accorded legislative recognition through laws that deny legal capacity to persons with disabilities. These laws disqualify persons with disabilities from taking their own life decision in matters of treatment, marriage or residence and prevent them from managing their own affairs by a blanket denial of contractual capacity. The CRPD has tried to remedy this deep discrimination by firstly recognizing that all persons with disabilities are persons before the law.³⁶ However this recognition is not confined to only reaffirming the legal identity of persons with disabilities as subjects of right. The Convention is also according to persons with disabilities the agency to manage their own affairs.³⁷ This agency is not grounded in the paradigm of independence but in that of

interdependence. The interdependence paradigm lays down that capacity and support can be co-terminus. A person with disability does not have to pronounce himself incapable in order to obtain support. Consequently the CRPD recognizes that a person with disability may need support to exercise capacity,³⁸ yet the obtaining of the support is no reason to conclude that capacity does not exist. This paradigm of interdependence which allows both autonomy and support to co-exist is a major advance that the Convention has made in establishing rights regime for persons with disabilities. In recognizing autonomy with support the CRPD has given voice to persons with disabilities, made persons with disabilities an integral part of the polity and thus accorded space to the disability perspective on the world.

III. Contribution of CRPD to human rights jurisprudence

The CRPD is the first human rights convention of the new millennium. To that extent its normative jurisprudence is not just of relevance to persons with disabilities but also important to all advocates of human rights. The convention requires special attention because it has what I term the wisdom of a straggler. By this, what I mean is that the CRPD gains from the mistakes made or the obstacles discovered in the working of the other human rights conventions. It is important to examine this convention for the fresh perspective it provides on the basic dilemmas of human rights advocacy.

Indivisibility of human rights

It has been long recognized that international human rights law has created a false dichotomy between civil and political rights, by one side, and social and economic rights, by the other. The Universal Declaration of Human Rights was a composite document incorporating civil, political, social and economic rights. However the succeeding conventions³⁹ introduced a divide between two sets of rights and further provided that whilst civil and political rights shall be immediately available; social and economic rights shall be progressively realizable. The logic for this difference of enforcement was situated in the manner in which the two sets of rights were classified. Thus whilst civil and political rights were termed negative; social and economic rights were seen as positive in their content. The presumption being that whilst States need to expand resources to uphold social and economic rights, no such correlative obligation needed observance in order to respect civil and political rights.

Henry Shue in his study on basic rights has exploded this myth.⁴⁰ It is Shue's thesis that it is incorrect to classify rights as positive or negative. He convincingly demonstrates that both civil and political rights and social and

economic rights give rise to positive and negative duties. The right to security for example is not realized just by the State observing its duties of avoidance whereby the citizen is not arbitrarily deprived of his right to life and liberty. The recognition of this civil right also requires the State to perform active duties of protection. And if it fails in providing protection it would need to extend aid be it to riot victims or civilian victims of war. For example the right to security cannot be guaranteed to citizens unless the state creates adequate infrastructure to protect the right. Hence Shue holds that the rights to subsistence and security should be guaranteed to all persons without quibbling on availability of resources; this is because without these basic rights it would not be possible to guarantee any of the other rights be they civil, political, social or economic. Unfortunately, despite its great logical and moral coherence Shue's thesis has not won the day in international law and the artificial dichotomy between civil and political rights and social and economic rights continues to be reiterated. The CRPD provides human rights advocates an opportunity to revisit this false division and once again set up a case for the indivisibility of rights.

The process of recognizing the rights of persons with disabilities mandated the creation of hybrid rights. For example the recognition of the right to speech and expression for persons with disabilities, provision has to be made for alternative and augmentative modes of communication, as without such provision the right would be meaningless. This connection that the CRPD makes between civil and political rights and infrastructure development is not unique to persons with disabilities; it is required for all persons. However by reason of the special needs of persons with disabilities this connection had to be made explicitly in CRPD. And as civil and political rights are immediately available, such like infrastructure development would have to be provided for contemporaneously and not progressively. Human rights advocates especially in the developing countries would be well advised to take note of this new development in the international law which could strengthen grass root advocacy for infrastructure development.

The indivisibility of civil and political rights, by one side, and social and economic rights, by the other, needs to be addressed not just when civil and political rights are provided for but also when provision is made for social and economic rights.⁴¹ Illustratively state programs in furtherance of the right to food can be planned and executed without participation of the beneficiary of the program. Such non-consultative upholding of rights undermines dignity and negates the choice of the beneficiary. Thus whilst the programs carry the label of rights the beneficiaries cannot assert these rights as claims without defense or shame. In fact such like programs are a continuous affront to the self respect of the beneficiaries. The CRPD has useful learnings on participation

rights in so far as it makes the right to participation a general obligation of the States. The States are required to consult with persons with disabilities on all policies and laws affecting them. This incorporation has transformed the slogan 'nothing about us without us' from a campaign anthem to a non-negotiable principle of disability rights. Yet again it would be appropriate for human rights advocates to learn from the CRPD and analogically extend the learnings of the convention to sites other than that of disability rights.

Human interdependence

The CRPD has not just reopened the issue of indivisibility of rights; it has also revisited the construction of the human. An examination of human rights instrument shows that the human has been constructed as a self-reliant and self-contained being who does not need anybody else. Feminist theory has convincingly demonstrated that this perception of self reliance and independence is a patriarchal myth.⁴² It is a patriarchal myth because the support which is obtained by the so called self reliant persons can be obtained without recognizing or acknowledging it in any manner. The public private divide allows men to make claims of self-reliance in the public domain as they can bank on the women behind the scene, to address their human neediness.

Persons with disability on the other hand possibly because of their impairments need to seek support in a more open and forthright manner. This explicit seeking of support makes possible the recognition of human interdependence. This recognition of interdependence is not a declaration of incapacity, but an honest acknowledgement that persons with disabilities may require support to exercise their capacities. This model is emancipatory not just for person with disabilities but for all of humanity. The model is emancipatory because it allows a person to admit deficits without feeling diminished. The model acknowledges the fact that we human animals are in need of each other.⁴³ The veracity of this proposition is borne out if a life course approach to the human life is adopted. There are very few stages in life that support the myth of self reliance. Childhood, adolescence, old age, and illness are obvious examples of human vulnerability and neediness. Humans have to and continually need to support each other in various kinds of ways but this mutual support in real life finds no juridical recognition. Consequently our jurisprudence continues to talk about independence. By setting up the paradigm of supported decision making, the CRPD unequivocally declares that it is possible to obtain support without being lessened or diminished. This paradigm of interdependence should be empowering and emancipatory for all of humanity and not just persons with disabilities.

Double discrimination

Another question which has constantly dogged human rights jurisprudence revolves around the issue of double discrimination. How should human rights jurisprudence address the vulnerability of those who are disadvantaged on more than one parameter? Be it gender combined with race or disability combined with ethnicity or age or gender. It is possible to come up with multiple formations of discriminated groups.⁴⁴ The question is how this double and multiple discrimination should be addressed. The issue of double discrimination came to the fore when the Women Convention had been negotiated. However at that juncture it was felt that any acknowledgement of multiple discrimination would dilute CEDAW's challenge of sex discrimination. Consequently except for a notional mention of rural women,⁴⁵ CEDAW constituted women as a universal category with this understanding that questions of double discrimination shall be addressed at the point of implementation.⁴⁶ Even as the Women's Committee has issued a General Comment on the rights of women's with disabilities⁴⁷ these promises relegated to the arena of implementation have been far from realized. The Convention on the Rights of the Child (CRC) answered the question of double discrimination a trifle differently in so far as a dedicated article on children with disabilities was included in the CRC.⁴⁸ This article was included in the CRC with the understanding that while the children with disability would be entitled to all the rights guaranteed in the CRC, their special interests would be taken care of in the dedicated article. Unfortunately the concern of children with disabilities was ghettoized in the dedicated article.⁴⁹ The CRPD was also required to engage with the issue of multiple discrimination. However, possibly because of the learnings from both the CEDAW and the CRC, the CRPD has devised a new strategy to address the issue of double discrimination, which can be termed the twin track approach.

This twin track approach guarantees to women and children both same and different. Thus whilst dedicated articles have been included in the convention to address the concerns of women⁵⁰ and children with disabilities,⁵¹ gender and age concerns have also been incorporated in several general articles of the CRPD on issues of special concern to these constituencies. Thus for example the article on liberty of movement and nationality explicitly mentions that children with disability shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and cared for by their parents.⁵² And the right to health expressly requires State parties to provide for health services that are gender sensitive.⁵³

With the adoption of twin track approach CRPD has devised a new strategy to address the issue of multiple discrimination. This approach requires that the

special concern of the vulnerable group be addressed in a dedicated article and simultaneously the general articles also take on board the distinct concerns of special groups. And thus the doubly discriminated should be doubly compensated. In so far as such discrimination is not only encountered by persons with disabilities, it would be appropriate for human rights advocates to engage with this new precedent in international human rights jurisprudence.

Right to participation

International law is an agreement between State parties; hence people have little role in the making of this law. In the more recent past efforts are being on to enhance peoples participation to curb this obvious disadvantage of international law. Ironically this induction of the perspective of the people is largely controlled by the will of the State. The negotiation of the CRPD as also the text which has emerged from these negotiations has put in place a new paradigm of people's participation.

The General Assembly resolution that setup the Ad Hoc Committee to negotiate the CRPD expressly required the State parties to arrive at the text of the Convention in consultation with civil society i.e. people with disabilities, organizations of people with disabilities, human rights institutions and other civil society associations.⁵⁴ This resolution of the General Assembly received the most liberal interpretation from the various Chairpersons of the Ad Hoc Committee. This resolution, interpretation and practice have established a new precedent on people's participation in the making of the international law. Even as these developments have occurred in the field of disability rights, their application need not be so confined. For wider application and analogical use it is important that human rights advocates closely study the manner in which the civil society participation was ensured during the negotiation for CRPD. A brief narration is hereby made in order to whet the advocacial appetite.⁵⁵

The setting up of a working group, to produce a working text was amongst the first decisions that the Ad Hoc Committee undertook towards its duty of reaching an agreed text for the CRPD. Insofar as the States as a whole would be reacting to the Working Group text, in the first place it was this working text which would form the basis for the proposed Convention. It is significant that organizations of people with disabilities along with human rights institutions were full members of this Working Group and optimally utilized this opportunity to educate State parties on issues and concerns of persons with disabilities. More significantly the working text which emerged from this process bore the indelible stand of civil society participation. This advantage obtained in the base text by organizations of people with disabilities,

significantly influenced the tone and tenor of negotiations in the Ad Hoc Committee. The participative right wrested by the organizations of people with disabilities in the Working Group was not surrendered by them at any juncture of the subsequent negotiations.

Ordinarily negotiations for international legal texts are undertaken in informal sessions and in order to aid flexibility and consensus no formal records are maintained of the deliberations in the informal sessions. Early in the negotiations for the CRPD it was resolved that civil society organizations will not have the right to speak in informal sessions. The informal sessions for CRPD occurred in the same room which was allocated for the formal meeting of the Committee. Thus though they did not have a right to speak, civil society organizations were allowed to remain present during the informal deliberations between States parties. Moreover as deliberation on any major article was concluded between States parties in the informal sessions, chairpersons took to convening formal sessions in order to provide opportunity to civil society organizations to express their views on the article under discussion. This near seamless switchover from informal to formal enabled the views of the people with disabilities and their organisations to be given full voice. On some of the controversial issues of the Convention thematic groups were constituted, wherein the views of people with disabilities and their organisations were generally sought and provided.

Ordinarily, even when civil society participation has been inducted during the making of international law; the negotiation of final texts has always occurred between State parties. The opinion of civil society has not been determinative of the process. The negotiations for CRPD have altered this practice of international law. As already mentioned the directive of the General Assembly was liberally construed in order to obtain inputs from people with disabilities and their organizations. To allow for efficient induction of the perspective of organizations of people with disabilities, persons with disabilities started to convey their opinion to the Ad Hoc Committee through an international caucus. The International Disability Caucus was a loose network formed at the United Nations by more than 70 international, national and regional disability organizations which were registered with the Department of Economic and Social Affairs (DESA). The unification of the disability voice substantially contributed the leverage acquired by people with disabilities and their organizations in the negotiation for the Convention. It is this leverage alone that explains why State parties towards the end of the process were unwilling to moot any textual proposal without obtaining the prior approval of people with disabilities and their organizations. The right to participation as constructed during the negotiations for the CRPD constitutes a precedent in international law which merits close study and replication.

The way forward

CRPD was opened for signature on 30th of March, 2007. A record 82 signatures were appended to the document on the inaugural day. Now that the CRPD has obtained the required 20 ratifications for the Convention and shall soon come into force, the Convention has become operative international law for the ratifying countries. The present international situation can be stated to be as follows: countries that have signed the CRPD; countries that have both signed and ratified and countries that have neither signed nor ratified the Convention.

This gap between signature and ratification also subsists because countries differ in the approach towards ratification and in the procedure by which countries induct norms of international law into municipal law. A number of countries do not ratify a convention till they have modified all domestic laws and policies and brought them into conformity with the international convention. For these countries the deposit of the instrument of ratification is no more than a formality as they would have fulfilled all their commitments emanating from the international instruments. Other countries take stock of the domestic situation and if they believe there is nothing in the international instrument with which they have disagreement they go ahead and ratify the instrument. It is important for civil society organizations to distinguish between the two processes of ratification and devise their advocacial strategies accordingly.

It is an established proposition in international law that a State is bound by the provisions of an international treaty only after it deposits the instrument of ratification. It is this proposition that causes organizations of people with disabilities to press early ratification by their respective countries. Even as the impatience of people with disabilities and their organization is understandable, it would rather unfortunate if this impatience may cause them to sacrifice the advantage obtained from the signature of the Convention. When a State party signs an international convention it undertakes that it shall not carry out any activity which is opposed to the mandate of the convention. Thus whilst ratification brings in a positive obligation signature inducts a negative duty. It would be unwise to accord no significance to this negative duty. At the very least this duty places an embargo on any other laws and policies which diminish the rights of persons with disabilities.

In conclusion I wish to refer to those kinds of tasks which disability rights activists can undertake to ensure that the promises of the CRPD are in fact be realized for persons with disabilities. International human rights law is arrived by consensus, and in the bid to obtain consensus, State parties perforce accept and agree to open textured language. This open textured

language then tends to create the impression that the demands of international human rights law are rather meager. A close study of the preparatory papers will show the various alternatives that were considered by the State parties, before consensus on the final text was reached. The open texture of the text masks this process. It is important therefore for disability rights activists to be aware of the various alternatives that were on offer, and use advocacy to lobby that the more aspirational interpretation be inducted in the national law. In this manner civil society can help raise the bar and prevent international law from being just an agreement on the least common denominator.⁵⁶

On another note the Convention has given birth to hybrid rights. Hybrid rights are those rights which have components of both civil and political rights, by one side, and social and economic rights, by the other. The creation of these rights has strengthened the indivisibility of rights discourse in human rights jurisprudence. The question is how would these rights be interpreted? Would they be dictated by the jurisprudence of civil and political rights? Or would they be guided by the theories surrounding social and economic rights? The ambiguous text of Article 4 (2) of the CRPD allows for either kind of interpretation.⁵⁷ It is therefore necessary that disability rights activists are quick on the draw and generate sufficient literature which would guide the policy and law thinking on rights of persons with disabilities.

Lastly the CRPD has provided new answers to some of the questions which have been dogging human rights jurisprudence for long. Illustratively questions on the entitlements of persons with psychiatric disabilities have been raised in the context of the Convention against Torture. It would be appropriate if instead of seeking answers all these questions in the Torture Convention alone, efforts were made to build bridges between the Torture Convention and the CRPD especially as the CRPD provides for rights to liberty, integrity, and legal capacity to all persons with disabilities. These rights can be employed to reinforce the mandate of the Convention against Torture. This strategy cannot be confined to the Convention against Torture similar initiative can be launched to strengthen the jurisprudence of the Women's Convention and the Child Rights Convention.

The unrelenting advocacy of persons with disabilities and their organizations has resulted in the adoption of the CRPD by the United Nation in record time. It goes without saying that this text shall greatly inform disability rights discourse from here on. However it would be unfortunate if normative and institutional innovations devised by the Convention are restricted in their application to disability alone. The Convention reconstructs both "human" and "rights" in human rights, it is therefore appropriate that human rights advocates engage with and draw on the learnings of this first human rights convention of the new millennium.

NOTAS

1. For a bibliography of writings on reforming the United Nations see <<http://www.un.org/Depts/dhl/reform.htm>>. Last visited on: 12 Apr. 2008.
2. MORIJN, J. *UN Human Rights Treaty Body Reform Towards a Permanent Unified Treaty Body*. Available at: <<http://www.civitatis.org/pdf/untreatyreform.pdf>>. Last visited on: 12 Apr. 2008.
3. Article 45(1) of the Convention on the Rights of Persons with Disabilities (CRPD) lays down that the Convention shall enter into force on the thirtieth day after the deposit of the twentieth instrument of ratification or accession.
4. BYRNES, A. *Convention on Rights of Persons with Disabilities*, presentation made at the Critical Legal Studies Conference at NALSAR Hyderabad India 1st to 3rd Sep. 2006.
5. For a comprehensive analysis of women's engagement with the United Nations see JAIN, D.. *Women development and the UN - A sixty year quest for equality and justice*. Hyderabad: Orient Longman Hyderabad, 2005.
6. Adopted by General Assembly resolution 48/96 of 20th Dec. 1993.
7. Proclaimed by General Assembly Resolution 2856 (XXVI) of 20th Dec.1971.
8. Proclaimed by General Assembly Resolution 3447 (XXX) of 9th Dec.1975.
9. Adopted by General Assembly Resolution 46/119 of 17th Dec. 1991.
10. CRPD. *Preamble*, paragraph f.
11. Illustratively Paragraph 5 of the Declaration on Mentally Retarded Persons declares that a mentally retarded person has a right to a guardian and article 12 of the Convention speaks of universal legal capacity and support to exercise capacity.
12. Standard Rules on the Equalization of Opportunities for Persons with Disabilities, rule 1.
13. *Idem*, rule 2.
14. *Idem*, rule 3.
15. *Idem*, rule 4.
16. *Idem*, rule 5.
17. *Idem*, rule 6.
18. *Idem*, rule 7.
19. *Idem*, rule 8.
20. *Idem*, rule 10.
21. *Idem*, rule 11.
22. *Idem*, rule 12.
23. Rights theorists make an important distinction between respect and policy rights. Whilst the first are absolute and non negotiable the latter are linked with resources and subject to negotiation. Socio-economic rights are generally referred to as policy rights in such categorization. Henry Shue

with his thesis on basic rights and SEN, A. Development as Capability Expansion. In: FUKUDA-PARR; S. & SHIVA KUMAR, A. K. (eds.). *Readings in human development*, 2003 and NUSSBAUM, M. *Frontiers of justice disability, nationality species membership*. New Delhi: Oxford University Press, 2006 with the capabilities approach are two efforts to attempt to promote at least some social – economic rights in a more unequivocal manner.

24. Henry Shue (SHUE, H. *Basic rights subsistence affluence and US foreign policy*. Princeton: University Press Princeton, 2nd ed., 1996) relies on Joel Feinberg (FEINBERG, J. *Social Philosophy*. Englewood Cliffs: Prentice Hall Inc., 1973) posits that the ability to demand it without shame is an integral component of a claim right. And it is because of this dignity that they confer on the rights holder that such rights are viewed as integral for promoting the innate respect of human beings.

25. CRPD, article 10.

26. Ibid, article 14.

27. Ibid, article 21.

28. Ibid, article 17.

29. Ibid, article 29.

30. Ibid, article 4(3).

31. Ibid, article 5(2) which requires states parties to “prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds”.

32. Ibid, article 2 defines reasonable accommodation to mean necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others all human rights and fundamental freedoms.

33. Ibid. article 5(3).

34. For information on the state of the law on legal capacity see DHANDA, A. Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future. *Syracuse Journal of International Law and Commerce*. New York, v. 34, n.2, 2007, p. 429-462,

35. CRPD, article 12 (1).

36. Thus article 12 (2) states that “states parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life”.

37. Article 12 (3) which requires states parties to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity”.

38. That is the International Covenant on Civil Political Rights adopted and opened for signature, ratification, and accession by General Assembly Resolution 2200 A (XXI) of 16th Dec. 1966. The Convention entered into force on 23rd Mar. 1976 and the International Covenant on Economic, Social and Cultural Rights adopted and opened for signature, ratification, and accession by General Assembly Resolution 2200 A (XXI) of 16th Dec. 1966. The Convention entered into force on 3rd Jan. 1976.

39. SHUE, supra note 24.

40. On the importance of the right to dignity see Nussbaum, *supra* note 23.
41. See especially YOUNG, I. M. *Justice and the Politics of Difference*. Princeton: Princeton University Press, 286 p., 1990.
42. For an extended treatment of this dimension of humanness see NUSSBAUM. *Frontiers of Justice*, *supra* note 23.
43. On a complex articulation of the phenomenon of double discrimination see FRASER, N. & HONETH, A. *Redistribution or recognition: A political philosophical exchange*. Verso, 2003.
44. Article 14 of Convention on the Elimination of Discrimination Against Women.
45. JAIN, *supra* note 5.
46. General Comment 18 was devoted by the Women's Committee on Women with Disabilities.
47. Article 23 on the Convention on the Rights of the Child.
48. Testimonies to this effect were made before the *AD Hoc* Committee on the CRPD by child rights advocates who had served on the Child Rights Committee. (Personal Notes on file with Author).
49. CRPD, article 6.
50. *Ibid*, article 7.
51. *Ibid*, article 18 (2).
52. *Ibid*, article 25.
53. GENERAL ASSEMBLY. Res 56/1681, 4 UN Doc A/RES/56/168 (26 Feb. 2002).
54. The following narrative has been written on the strength of the notes that I have maintained as a NGO delegate from the 3rd to 8th Meeting of the *Ad Hoc* Committee that is from June 2004 to Aug.2006.
55. Interestingly article 4 (4) of CRPD expressly allows States Parties to recognize more than the Convention.
56. Section 4(2) provides with regard to economic, social, and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed within the framework of international cooperation with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.

RESUMO

O artigo examina a Convenção sobre os Direitos das Pessoas com Deficiências, que é o primeiro instrumento de direitos humanos do milênio a entender como o discurso dos direitos das pessoas com deficiências tem sido alterado e a contribuir para a jurisprudência sobre direitos humanos. Isso ocorre porque a Convenção altera o léxico dos direitos das pessoas com deficiências e oferece um novo insight sobre o modo de resolver alguns dilemas perenes dos direitos humanos.

PALAVRAS-CHAVE

Pessoas com deficiências – Assistência social – Discriminação – Autonomia – Indivisibilidade – Participação

RESUMEN

Este artículo examina la Convención sobre los Derechos de las Personas con Discapacidad, que es el primer instrumento de derechos humanos del milenio en comprender cómo el discurso de derechos de personas con discapacidad tiene sido alterado, y cómo el contribuye a la jurisprudencia de derechos humanos. Esto se debe a que la Convención modifica el léxico de derechos de discapacidad y ofrece un entendimiento novedoso sobre la manera de resolver algunos dilemas perenne de derechos humanos.

PALABRAS CLAVES

Personas con discapacidad – Asistencialismo – Discriminación – Autonomía – Indivisibilidad – Participación

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