Disability Rights

An American Invention – a Global Challenge.

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Disability Rights

An American Invention – a Global Challenge.

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1. Introduction.

Good afternoon. Thank you so much for the honour and privilege of presenting the annual Valerie Gordan lecture. My topic is disability – more specifically I want to talk about progress towards the drafting of a new international convention on the rights of persons with disabilities.

When all the rhetoric is boiled away and when legal niceties are put to one side (where they generally belong) my talk is really about human difference. It is about the value we place on difference within our democratic societies. I will not directly address the interesting academic debate about how difference is constructed. My core focus is on how people who are labelled 'different' on account of their disability are treated.

In her life Valerie Gordan worked hard to generate respect for the difference of colour and ethnic background. My work is geared toward generating increased respect for the human difference of disability. Our common work is therefore of a piece – it is to re-make the world into a place where the diversity of the human family is a cause for celebration and not a ground for exclusion. I hope to do justice to her memory here today and to this joint cause.

Allow me to digress for a moment before proceeding to the main topic at hand. I think the mere fact that we are gathered here today in her honour demonstrates several unspoken things that unite us. I believe we are united by a common belief in justice. Justice is a deeply contested political and legal ideal – and rightly so. Yet I doubt if anyone in this room would question basic universal values such as dignity, autonomy and equality which lie at the very base of our shared conception of justice. It is exactly these values that are directly implicated in the disability rights debate.

Valerie Gordan also believed in another ideal component of justice – namely social solidarity or social justice. I stand with her on this although I know the place of social

justice is much less secure than it ought to be within our respective legal and political orders.

I think we are also here because of our faith – perhaps a naive faith – in the possibilities of doing justice through law. We know only too well how law can be an engine of injustice and oppression. May I remind you that there was a league of Nazi lawyers in Germany dedicated to a new form of law – one that brutalised people and all in the name of the law[1]. With Roscoe Pound we know only too well the imperfections of the legal order and its natural tendency toward decay[2]. Yet, with Robert Kennedy, we also know that the highest and most noble aspirations of human civilisation can find no clearer expression – no better imprimatur - than through the law of the land. As lawyers, we take collective pride in the accomplishments of the legal order. As lawyers we feel – or should feel – shame and a share of personal responsibility for its failings. We all have a stake in its reform.

So I am involved in the disability rights debate partly because of my general interest in justice and partly because of my interest in the uses and limits of law as an engine of justice. But that is not all. Our first child was born fifteen years ago this month with Spina Bifida. Her name is Niamh – which means 'ray of sunshine' in ancient Gaelic. She was the jump spark connection that brought an inert interest in law to life. It is from her and countless millions like her that I draw my energy. I trust my personal experience does not detract from the objectivity of my analysis this evening – but rather adds an edge to it that it might otherwise lack.

What then of disability and of the disability rights movement? You may be amazed to learn that there are 600 million persons with disabilities in the world. About 500 million live in developing countries where they share the general disadvantages faced by all – and then some. It is reported that less that 1% of children with disabilities get any form of schooling in many developing countries. You don't have to go to developing countries

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1 See e.g., Micael Stolleis, **The Law under the Swastika**, Chicago U Pressd, 1994.

2 Roscoe Pound, *Mechanical Jurisprudence*, 8 Vol L. Rev. (1908) 605.

to find deplorable conditions. Mental Disability Rights International (MDRI) recently reported on the practice of welding bed cages shut over disabled children in institutions[3]. Most people with disabilities live in dire poverty. They are not viewed as human capital – ready, willing and able to work and otherwise contribute. Instead they are viewed as objects of pity, as passive recipients of State largesse (if any). The truth is, we are all developing countries when it comes to disability.

My talk is about how the difference of disability is viewed negatively – not just in societies throughout the world but also in the world of basic values and also in the world of law. Put positively, it is about the worldwide trend in favour of restoring visibility to disability in values and in law. The latest manifestation of this positive trend comes in the form of the draft treaty on the rights of persons with disabilities.

2. The World of Values – and the Invisibility of Disability.

What's wrong with this negativity? To me the disability debate brings into sharp focus the question how human difference is to be responded to and how basic humanity ought to be respected regardless of the difference in question.

Lets first talk the language of justice before talking the language of rights and law. For our notion of justice frames how we view reality including the reality of persons with disabilities, how we judge that reality and the kinds of blueprints for change that we propound. Take each of the foundational values of our political and legal order – indeed of the international political and legal order.

Take the postulate of human dignity which encapsulates the simple idea that all persons are ends in themselves. In practice, most of our market driven societies value human beings for their use-value. If your use-value is diminished (or more to the point, if it is perceived as diminished) then your human value also tends to fall. The reality is that

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[3] MDRI, **Human Rights & Mental Health: Hungary** (1997): www.mdri.org/report%20documents/Hungary.doc

many people with disabilities are treated as objects and not as subjects throughout the world. It is this objectivisation of the human spirit that demeans us all.

Take the value of autonomy, the simple idea that each person is self-governed and goal directed. Yet we often we deny people with disabilities a right to make decisions over their own personal destiny. Only recently has there been much movement to provide them with the means for leading independent lives. Surely the correct response to those with diminished capacity for autonomy – or who are perceived as having such a diminished capacity – is to assist people to lead independent lives and not to substitute our views for theirs.

Take the related value of equality. We are not only of inestimable personal value but our values are equally inestimable. Yet it is striking just how often this basic postulate is lost in the context of disability. There are of course many renderings of the equality idea.[4] At its most basic it insists that public benefits and burdens fall equally and fairly on those who are similarly situated. It must, perforce, take account of those who are differently situated and make appropriate adjustments in order to make the promise of equality real and not illusory.

And here is the core of the problem. To do this – to take sufficient account and to positively value the difference of disability - requires action and not merely abstention. Yet our legal orders have historically resisted such mandatory action partly out of deference to the separation of powers and partly because of its innate hostility to distributive justice. Our legal orders are historically disinclined to direct power – they are more used to challenging particular uses of power. What we typically call for in the disability field are two things; firstly that the difference of disability should not be used negatively and secondly, that positive account should be taken of the difference.

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[4] For a useful and clear discussion of the various models see e.g., Sandra Fredman, **Discrimination Law**, Oxford U Press, 2002.

Interestingly, the equal opportunities model looks both ways – it adequately frames a concern for the negative use of difference by banning discrimination based on disability and it makes a stab at enjoining positive action. It is a sort of way-station half way between formal and distributive justice – a way station that seems to meet with the exigencies of our market driven societies.

Take the value of social solidarity. Most (!!!) would agree that we owe something to each other. We cannot simply ignore the fate of our fellow man. Such wilful ignorance detracts from our own sense of humanity. Most countries do in fact put in place a web of social supports for people with disabilities. These supports tend to entrap more than liberate the person. One gets the feeling that they purchase the absence of the 'other'. To paraphrase Justice Brennan, they place persons with disabilities less on a pedestal and more in a cage[5].

One problem with this value system is its bias against distributive justice. Don't get me wrong. I don't argue that our legal systems are inherently unjust. Its just that there is an inbuilt bias against distributive justice – a bias that clearly emerges when discussing justice for a group like the disabled who often require concrete support to complement legal protection. Of course, this in-built bias affects all groups and not just the disabled. But it has pronounced effects on persons with disabilities.

But by far the main problem with these values is that we do not apply them consistently. It is as if our cultures carve out 'no-go' areas where these values are not supposed to operate. I recall the words of Blackstone – the famous English legal historian – who once wrote that, upon marriage, women suffer civil death in the sense that all the indicia of her legal personhood were merged in that of her husband[6]. It has been remarked by many that the history of gender law reform ever since has been a history of gradually restoring the indicia of full legal person to women. In a sense, gender law reform is a history of restoring visibility to the person.

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5 Frontiero v Richardson, 4111 U.S. 677 (1973).

6 Blackstone's Commentaries on the Laws of England, *430.

Likewise, I like to think of the disability project as a visibility project. We like to remind society that people with disabilities are not 'problems' – they have rights and equally legitimate expectations. They are not objects – they are subjects just like you and I. It is amazing just how difficult this first step is.

I believe the separateness of persons with disabilities – a separateness caused by public policy – is treated as 'natural' or 'normal' throughout the world. It is as if the odious 'separate but equal philosophy' is still accepted in many parts of the world today with respect to persons with disabilities. This doctrine has no place in race – it should be equally resisted for other groups.

3. The World of Law – and the Invisibility of Disability.

Now lets talk law. Our legal orders are dedicated to the values of dignity, autonomy, equality and (more or less) solidarity. Yet the same invisibility of persons with disabilities in the world of values is reflected in the world of law. That is, the same discounting of persons with disabilities that took place in the realm of values also takes in place in the realm of law.

Take civil rights. The civil rights continuum honours and protects the personal zone. It protects the very basis of citizenship through the right to life and through freedom from torture, inhuman and degrading treatment. It opens up possibilities for self-expression through liberty and related due process protections. It creates manifold possibilities for achieving goals in common with others through freedom of association. However, at each and every point in the civil rights continuum you will find the discounting of persons with disability. You don't have to search far to find Eugenic practices in the world[7]. Inhuman and degrading treatment seems normal especially in many institutional

[7] See Catherine Cleary, The Irish Times, *Dark Shadow on a Modern State*, August 30, 1997 , p 10 (discussing compulsory sterilization in Sweden over a 40 year period until the mid-1970s).

settings[8]. Due process protections are notable by their absence throughout much of the world in the field of civil commitment[9]. International law is not well developed on the right to consent, on the right to treatment, on the right to refuse treatment and on prohibiting certain forms of treatment. Association rights are chilled when it comes to intimate relations. Even parents with disabilities find it hard to adopt children.

Take political rights. How can people with disabilities exert a pressure commensurate to their numbers if they cannot access polling stations or read accessible political information?[10] Even if they can, will they necessarily be listened to? Are they – to use the colourful language of Footnote 4 of the Caroline Products Case – a genuine 'discrete and insular minority'. I believe they are. In any event, why should their rights depend on their numerical strength or political clout? Why is it that our systems cannot respond out of principle and not simply as a response to pressure. The answer, I suggest, has a lot to do with the invisibility of disability in the political process.

Take economic, social and cultural rights and entitlements. These rights do not exist for their own sake. Still less do they necessarily indicate a collectivist political philosophy. They are there to provide a material underpinning to our commitment to freedom. Yet, these rights often have the effect of cementing into place the very isolation of persons with disabilities to which we loudly profess our objection. The reality is that most socio-economic programmes targeted at persons with disabilities have resulted from pressure politics or from pity – not from principle. And if such programmes respond to pressure they respond to those who exert the strongest pressure and not necessarily to those who are in greatest need[11]. Among other things, this allows Governments to play one impairment-specific group off against the other.

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[8] For a review of abusive practices in mental institutions throughout the world see Mental Disability Rights International www.mdri.org/aboutus/Record.htm.

[9] See website of the World Network of Users and Survivors of Psychiatry (WNUSP) www.wnusp.org/ (who take the view that civil commitment is a per se violation of human rights).

[10] See the Bill for Electoral Rights for Citizens with Disabilities put together by the Global Initiative to Enfranchise People with Disabilities : www.electionaccess.org/rs/Bill_English.htm

[11] See General Comment 5 of the UN Committee on Economic, Social and Cultural Rights on the relevance of these rights in the context of disability (1994): www.unhchr.ch/tbs/doc.nsf/(Symbol)/4b0c449a9ab4ff72c12563ed0054f17d?Opendocument.

So disability is not visible within values and within the law. How then can the 'visibility' project be advanced?

4. The Inspiration of the United States – Restoring Visibility.

This latter question is why US disability law of interest to the world.

Henry Steele Commanger once wrote a book entitled 'How Europe Invented and America Perfected the Enlightenment'. There is something to the assertion that the rational principles of the Enlightenment, which were so carefully crafted by the French Encyclopaedists and others in the 18th century, could only have been pushed insistently to their logical extremes in a culture unencumbered by the dead hand of history.

Allow me as a foreigner to say that one of the strengths of the United States is that nothing unites it – except fidelity to these general values of dignity, autonomy and equality. It is a nation built on ideas and values – and not on ethnic homogeneity. We too are trying to build a European Union bound together by ideas and not by mutual national antagonism. But the dead hand of history is harder to overcome on a continent filled with the shadows of the past.

The beauty of such a value-based political construct is that it behoves each generation to confront itself with these values. Each generation adds something to these values. Sooner or later (usually later) pressing problems get referred back to the underlying values of the system. Don't get me wrong. This is no apologia for complacency. It is of course entirely possible – indeed probable - to loudly profess one set of values then systematically practice the exact opposite without even experiencing any sense of contradiction. Hypocrisy seems deeply ingrained in the human condition! Yet the presence of governing values hanging over the system at least allows one an opportunity to challenge the gap between reality and principle and to agitate peacefully for change.

The habit of periodically checking practice against principle is healthy and seems more possible in a country dedicated (in form at least) to principle. Your Supreme Court looked into the soul of the nation in 1954 and denounced the 'separate but equal' philosophy as a violation of the principle of equality before the law. Your nation was forced to look at itself in a mirror. It took a long time – but it did happen. And its not over yet.

The enactment of Section 504 in the Rehabilitation Act of 1973, the passage of the Education of All Handicapped Children Act of 1975 (subsequently renamed the Individuals with Disabilities Act), the passage of the Air Carriers Access Act in the 1980s, the enactment of the Fair Housing Amendment Act of 1988 and, of course, the enactment of the Americans with Disabilities Act in 1990 – all of these acts stand for something important.

From the worm's eye view – from your view – these Acts represent temporary and perhaps flawed attempts to give meaning to equality for persons with disabilities. There is a backlash[12]. We all watch and wait for the outcome in Tennesse v Lane. The US Supreme Court does not tend to view the ADA as the civil rights statute it was intended to be. Their judgments excite outrage – outrage which only serves to heighten the gap between reality and principle and which, if marshalled effectively, can lead to legislative improvements.

And yet, from the bird's eye view – from my view as a foreigner - this corpus of law is remarkable not for what it is but for what it stands for. It symbolises an attempt (maybe not an entirely successful attempt) to treat persons with disabilities as subjects and not as objects – to give them visibility as human persons. This symbolic move motivates millions beyond your borders.

[12] See,. E.g., Linda Hamilton Krieger, **Backlash against the ADA – Reinterpreting Disability Rights**, (Mich. U Press 2003).

That is one reason why I would like the United States to take a much more active involvement in the drafting of the proposed treaty on the rights of persons with disabilities.

5. International Law – a Slow Start.

Well then, how fares the Enlightenment habit of periodically adjusting practice to meet principle in international relations – bearing in mind that the bulk of persons with disabilities live in developing countries? How fares the visibility project under international law?

International human rights law was meant to provide an effective platform for precisely such a process of self reflection and adjustment[13]. It is composed of two general treaties

- the International Covenant on Civil and Political Rights (ICCPR), and
- the International Covenant on Economic, Social and Cultural Rights (ICESCR) dealing respectively with civil and political rights and with economic, social and cultural rights.

It is also composed of three 'thematic' treaties dealing with the general rights as applied to three different 'vulnerable' groups;

- Women (Convention for the Elimination of All Forms of Discrimination against Women - CEDAW),
- Children, (Convention no the Rights of the Child - CRC) and
- Racial Minorities (Convention on the Elimination of Racial Discrimination – CERD).

[13] For a review of the current human rights treaty system see generally Steiner & Alston, **International Human Rights in Context**, (2 Ed., Oxford U Press, 2000).

There is also one extra thematic treaty focused on the substance on one right; torture (Convention against Torture - CAT). All the treaty monitoring bodies set up under these treaties review periodic State reports and some have the capacity to entertain and adjudicate individual complaints.

You might expect that the machinery set up under these treaties would have produced a substantial volume of jurisprudence by now on the relevance of the rights in the context of disability. Wrong!!! The General Assembly issued a Declaration on the Rights of Persons with Disabilities in 1975 declaring that persons with disabilities enjoyed all the same rights others[14]. What is remarkable about the resolution is the fact that it was felt needed in the first place. Apparently some States had even suggested that because persons with disabilities were not explicitly mentioned in the existing human rights treaties that they were not covered!

There were and are very many general human rights NGOs. However, they did not typically see disability as a human rights issue. The disability NGOs were not themselves equipped to exploit whatever opportunities they had to ventilate claims before the relevant treaty bodies. Even if they did, they may not have met with much success. No one with a disability has ever been nominated – much less appointed – to one of these bodies. The treaty bodies are drawn in many different directions and have precious little space to focus on and develop a depth of insight into disability. In any event, the philosophy of 'separate but equal' has proven much more resilient throughout the world in the disability context and might have been endorsed by these treaty bodies if the 'wrong' test case came before them.

In 1982 the UN inaugurated the World Decade of Action for Persons on the back of a Work Programme for Persons with Disabilities[15]. An independent review was set up in the late 1980s to assess progress achieved and obstacles encountered. Predictably nothing much positive could be reported. It came to the unanimous conclusion that a

[14] General Assembly Resolution 3447 (XXX) of 9 December 1975.

[15] World Programme of Action, General Assembly Resolution 37/52, 3 December, 1982. For a set of basic documents see Degener & Koster-Dreese, **Human Rights and Disabled Persons**, Nijhoff 1995.

hard legal treaty was needed to tailor the general human rights contained in the ICCPR and ICESCR to the specific situation of persons with disabilities. In other words, it advocated exactly the same kind of thematic rights treaty for persons with disabilities as had already been elaborated for women, children and racial minorities. Italy and Sweden even proposed draft texts. However, the General Assembly rejected the proposal mainly because of treaty fatigue. This was a wasted opportunity.

Instead it passed a special resolution containing the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities[16]. This is an admirable document. Note the emphasis on equality of opportunities. And, unusually for a 'soft law' resolution, it made a stab at creating an 'enforcement mechanism'. It set up an Office of UN Special Rapporteur on the Standard Rules. Interestingly, the Special Rapporteur reported to the UN Commission for Social Development in New York and not to the UN Human Rights Commission in Geneva. That fact alone revealed a lot about how disability was still viewed as a social policy issue instead of a rights and justice issue as late as 1993.

Throughout the 1990s a number of interesting things happened to create a better chance for securing a treaty. The early success of the ADA in the 1990s was a vital factor. It emboldened many to project the ADA's underlying principles in international law. In a recent book commissioned by DREDF (Disability Rights Education Fund) and funded by the US Social Security Administration, Theresia Degener and I identify over 40 nations that have – in one way or another – emulated the American example[17] - call it socially justifiable plagiarism!

Europe was slower to respond but is fast catching up. Throughout the 1990s the European Union – headquartered in Brussels - aspired to become more than just an arrangement for a common or Inter-State market. It always had strong powers in Inter-

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[16] UN Standard Rules on the Equalisation of Opportunities for Persons with disabilities, General Assembly resolution 48/96, 20 December 1993.

[17] Gerard Quinn & Theresia Degener, *'A Survey of International, Comparative and Regional Disability Law Reform'*, in ch. 1 Mary Lou Breslin & Silvia Yee, **Disability Rights Law and Policy – International and National Perspectives**, (Transnational, 2002)

State Commerce. But they were never used for social purposes. It accreted new legal competences over the Member States in the field of equality and non-discrimination. Article 13 of the Treaty of Amsterdam (1997) added a hard competence to enact discrimination Directives which take precedence over national law – even national constitutional law – to the contrary[18]. In EU law Article 13 plays a similar role to your 14th Amendment – similar but not exactly the same. On foot of this new power, the Council of Ministers of the EU (its supreme legislative body) adopted a landmark Framework Directive in 2000 on employment – forbidding discrimination based on a number of grounds including disability and enjoining employers to provide 'reasonable accommodation'[19]. You will note that even if Europe invents ideas and America perfects them, we can still take them back!

The Council of Europe – which is Europe's premiere human rights regional organisation and which is headquartered in Strasbourg – itself issued a landmark policy document in 1992 on a coherent policy for persons with disabilities[20]. Recently a Ministerial Conference of the Council of Europe – which now contains over 40 Member States including Russia – announced its intention to initiate a ten year strategy aimed at assuring equal rights for persons with disabilities[21]. Interestingly, the Council of Europe does allow collective complaints on the basis of alleged 'violations' of social rights. Recently Autisme France won a landmark case against France for the slow rate of progress in mainstreaming or otherwise providing for autistic children[22]. I encourage those of you interested in education law to read it.

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[18] For a history of EU involvement see Gerard Quinn, **'Human Rights and Disabled Persons'**, in Alston *et al*, **Human Rights and the European Union** (Oxford, 1999). See also Mark Bell, **Anti-Discrimination Law and the European Union**, (Oxford U Press, 2002).

[19] Full text of Directive available at www.europa.eu.int/comm/employment_social/fundamental_rights/pdf/legisln/2000-78_en.pdf

[20] Recommendation available at www.cm.coe.int/ta/rec/1992/92r6.htm

[21] Malaga Political declaration available at www.coe.int/T/E/Social_Cohesion/soc-sp/Integration/03_Ministerial_Conferences/2nd_Conference_Malaga_2003/default.asp#TopOfPage

[22] Social Charter Decision on the Merits: www.coe.int/T/E/Human_Rights/Esc/5_Collective_complaints/List_of_collective_complaints/RC13_on_merits.pdf

Closer to Boston, the Organisation of American States adopted a convention on discrimination against persons with disabilities in 1999[23]. As far as I know the US has not ratified this treaty.

Finally and at the global level (and not without time) the UN Commission for Human Rights – headquartered in Geneva - began to take an active interest in disability. This is the UN's premiere political body on human rights matters. A bi-annual resolution on disability and human rights was passed by the Commission through out the 1990's. It helped matters that Mary Robinson – former President of Ireland – became the UN High Commissioner in the late 1990s. Her Presidency was remarkable in how she reached out to persons with disabilities and many others. Ireland had carriage of this resolution for much of the late 1990s. It had previously won the prestigious Roosevelt Institute international disability award in 1999[24] and was strongly motivated to try to bring the issue onto the international agenda.

Our Ministry of Foreign Affairs approached me and a number of others in 1999 concerning its draft text of the resolution for 2000. We all said that the resolution should revive the idea of a treaty. The Ministry agreed and we inserted some draft language into the proposed text. However, two of our EU partners intimated that they were opposed (rumoured to be Sweden and the Netherlands). We had to withdraw. But the intention was to regroup and not to give up. Our Ministry commissioned research from myself and Professor Theresia Degener on the current functioning of the existing treaty system in the disability context. The idea was to publish the research and thus create a political clearing before the issue would next come up before the Commission in the Spring of 2002.

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[23] OAS Convention: http://www.oas.org/main/main.asp?sLang=E&sLink=http://www.oas.org/juridico/english/treaties.html

[24] See, www.feri.org/awards/disability.cfm

The resulting Study demonstrated how the existing treaty machinery was not working in the context of disability[25]. It identified positive normative potential in the treaties in the disability context and made several practical recommendations geared toward making the existing system work better. But the heart of the Study contained a series of arguments as to why a new treaty was needed – one that would underpin and not undermine the existing system.

Meanwhile, Mexico changed Presidents! Vicente Fox decided to make disability a top international priority for his Administration. The Mexican Government managed to get some disability-friendly language into the Durban Declaration on Race (World Conference against Racism)[26] and then proposed a resolution before the UN General Assembly in December 2001 which would have called for the process to draft a treaty to begin forthwith. The EU was having none of it! It threatened to veto the resolution. But it held back out of deference to the newly elected President of Mexico. Instead, it allowed the resolution through on the basis that a new Ad Hoc Committee of States would be set up to merely 'consider proposals' for the drafting of a treaty[27]. In other words, the EU was probably hoping that the Ad Hoc Committee would, after considering such proposals, decide not to proceed any further or else send the matter to the UN Human Rights Commission in Geneva where it was felt it properly belonged. Diplomacy is an interesting world!

The Mexican resolution was adopted by the General Assembly in December 2001 and our Study was published in February 2002 just in time for the Spring session of the UN Human Rights Commission. But by now the Geneva route was blocked pending the success or failure of the Ad Hoc Committee in New York.

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[25] Gerard Quinn & Theresia Degener et al, **Human Rights and Disability – The current use and future potential of the United Nations human rights instruments in the context of disability**, (United Nations, Geneva, 2002). See web version: www.unhchr.ch/disability/study.htm

[26] See www.unhchr.ch/html/racism/02-documents-cnt.html

[27] Resolution, December 2001, A/RES/56/168.

The First Ad Hoc Committee session – a two week session- was due to take place in late August 2002[28]. In June of that year the Mexican Government convened an 'expert' seminar in Mexico City and there presented its own draft text. I was privileged to have been there.[29] We pointed out the many areas that the Mexican text had neglected. It looked more like a social policy tract. We drafted an Indicative Outline of the kinds of rights the treaty should contain. We drafted Principles concerning the manner by which the treaty should be drafted. This work proved influential at the first session of the Ad Hoc Committee in August 2002 held in New York.

The proceedings of the August 2002 Ad Hoc Committee were difficult. I was privileged to have been part of the official Irish delegation. It was clear to me that most delegations had no clear instructions from their capitals. It was clear that while the treaty had some champions (including the UK, Denmark and Germany) it was also had many implacable opponents. Eventually the Ad Hoc Committee decided to continue the process of 'considering proposals' for the elaboration of a treaty. Interestingly, the Ad Hoc committee made one procedural innovation. It opened up possibilities for disability NGOs to participate in the proceedings. Such NGOs do not necessarily have to have consultative status with the UN. So a local disability NGO here in Boston could attend and participate!

A second session of the Ad Hoc Committee was scheduled for June 2003. I was not present during that session. At last the second session did the decent thing – it decided to set up an expert Working Group to begin the task of drafting a clear text for the consideration of the Ad Hoc Committee[30].

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[28] For full background documentation to the process including up-to-date draft texts see www.un.org/esa/docdev

[29] Documentation on Mexican Government expert seminar available at www.sre.gob.mx.discapacidad

[30] For document and outcomes of the Second Session of the Hoc Committee see www.un.org/esa/socdev/enable/rights/adhoc2meet.htm

The Working Group met for the first two weeks in January 2004. It was composed of 27 States (finely balanced from all regions of the world) 12 global NGOs and 1 representative of world human rights commissions (South African Human Rights Commission). One of the global NGOs was Rehabilitation International (RI) which is headquartered in New York. I was privileged to be the lead delegate of the RI delegation to the Working Group[31].

There were very many draft texts before the Working Group prepared by many States and others. Perhaps the most admirable of these was the one prepared by a regional workshop on the draft treaty in Bangkok, Thailand (so-called Bankok draft)[32]. Several countries submitted draft texts or detailed proposals including the European Union, China, India, Costa Rica, Japan, New Zealand. The ILO and UNICEF made submissions as did several international disability NGOs such as Inclusion International, World Network of Users and Survivors of Psychiatry, etc. The United States contributed a memo outlining its legislation in the field[33].

The important point to remember about the text elaborated by the Working Group is that it goes back to the Ad Hoc Committee which will resolve all outstanding issues of principle. And the Ad Hoc Committee is of course primarily a political body.

6. The Working Group Text.

The chair of the Ad Hoc Committee (ambassador Galleagos of Ecuador) opted not to chair the Working Group. Instead the Working Group was chaired by a very able New Zealand diplomat – ambassador David McKay. The very first act of David McKay was to propose that the Working Group proceed on the basis of a composite draft put together by ambassador Galleagos. The Galleagos text drew together the assimilable portions of all other texts on the table. This proposal met the ire of the EU which wanted the Working Group to use its text as the basis for negotiations. Eventually the chair won on

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[31] I was ably assisted by Aaron Dhir (Canada), Mariyam Cementwala (California) and Rosemary Kayess (Australia).

[32] Bankok draft: www.un.org/esa/socdev/enable/rights/bangkokdraft.htm

[33] US Memo: www.un.org/esa/socdev/enable/rights/wgcontrib-usa.htm

the issue – partly because the EU only contains a minority of the world's disabled population. But since the text we elaborated will have to go back to the Ad Hoc Committee in May/June there is at least some suspicion that the EU will submit amendments that go to its heart[34]. The US was not a member of the Working Group – something that I regret. It was of course present but had no right to contribute or vote. So the EU has left to speak for the West.

The draft text elaborated by the Working Group has many fine features[35]. The purpose of the convention is set out in draft Article 1: "to ensure the full, effective and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities." This wording is quite important. One gets the feeling that the EU was more interested in a bald non-discrimination treaty. That is, the EU did not want to get into the substance of the rights (which includes economic, social and cultural rights) but wanted to put the focus on a controlling principle like non-discrimination. We in RI thought it illogical to focus on non-discrimination without focusing on the substance of the rights to which the non-discrimination principle would apply. We won – at least for the moment.

Draft article 2 sets out general principles such as dignity, autonomy, non-discrimination, inclusion, respect for difference and equality of opportunity. So far so good. Draft article 4 sets our general obligations on States Parties including the obligation to mainstream disability issues into all policy programmes and in active consultation with people with disabilities and their representative organisations. Draft article 5 deals with an obligation to promote positive attitudes towards persons with disabilities. Draft article 6 requires the collection of useful statistics – that is to say it requires that rational policy should be based on an accurate assessment of the situation.

Draft article 7 deals with the principles of non-discrimination and equality. The debate was vexed. Most of us in the NGO sector wanted to see a direct link drawn between failure to reasonably accommodate a person with a disability to the non-discrimination

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[34] For a detailed day-to-day account of the meetings see: www.rightsforall.org/updates2004.php

[35] For the draft text of the Working Group see www.un.org/esa/socdev/enable/rights/ahcwgreportax1.htm

idea. That is, we wanted to see a failure to provide reasonable accommodation as a violation on the obligation not to discriminate. The EU would not go along. They wanted this obligation linked to – but essentially separable from – non-discrimination. Several technical reasons were given. But the real reason was clear enough to me. Since this will be a treaty spanning both civil and political rights as well as economic, social and cultural rights the EU was probably fearful that the remedies that might obtain with respect to an alleged violation of civil and political rights might also begin to seep into the zone of distributive justice. This seepage is not something it would welcome. That is why there is such an elaborate footnote (fn 27) to draft Article 7.(4). In other words, the issue is bracketed for decision at the next session of the Ad Hoc Committee.

Draft article 8 deals with the right to life. As you can imagine this gave rise to some heated debate. I believe that a treaty on disability without some coverage of the right to life would be flawed. In Mexico we proposed in our Indicative Outline something along the following lines: "the prohibition of policies that encourage abortion on the basis of disability". This was the closest we could come to any consensus. In any event, I'm sure You can guess this will continue to be a point of contention at the next Ad Hoc session.

Draft article 9 deals with recognition before the law. In reality it deals with the issue of competence. There has been a huge amount of law reform throughout the world on competence including one treaty concluded within the Hague Conference on Private International law[36]. Many of the sentiments found in draft article 8 are to be found in a highly impressive Council of Europe Recommendation dealing with the legal protection of incompetent adults.[37] One disability NGO –WNUSP – took the view that there is no such thing as an incapable adult and that any principles governing intervention – no matter how fine - are redundant. That is, there should be no intervention – period. Again, you can see why this is an important issue of principle which the next session of the Ad Hoc Committee will have to deal with. The same issue hangs over draft article 10

[36] Hague Conference Convention no 35 on the International Protection of Adults (2000): www.hcch.net/e/conventions/text35e.html

[37] Recommendation R (99) Principles Concerning the Legal Protection of Incapable Adults: www.cm.coe.int/ta/rec/1999/99r4.htm

dealing with liberty. WNUSP takes the view that all incarcerations on the grounds of mental health are illegitimate.

Draft article 11 deals with protections against cruel, inhuman or degrading treatment. Its good so far as it goes – but it should go a lot further. Draft article 12 on freedom from violence and abuse is very useful. It covers the home as well as institutions. It reaches all forms of exploitation including sexual exploitation. Draft article 13 deals with freedom of expression and access to information. Usefully it refers to the provision of information in accessible formats. The obligations are not as tight as they might be. Draft article 14 deals with respect for privacy and family life. Again, very usefully it deals with the right to marry, found a family and adopt and also for right for children not to be forcibly removed from their families.

Draft article 15 deals with the right to live independently and to be included in the community. This is huge step forward. Among other things it would ensure a right o choose a place of residence and living arrangements. It would assure one of a right not to live in an institution and to have access to a range of community supports. Draft article 16 deals with children with disabilities and seeks to assure them 'the same rights and fundamental freedoms as [are enjoyed] by other children'. Of especially importance here are the early provision of appropriate and comprehensive services. Draft article 17 focuses on the right to education. It includes a strong reference to inclusive and accessible education. One issue here was the place of special education. I have to report that two global disability NGOs supported special education from the perspective of specific impairments –blindness and deafness. I understand their preoccupations. This issue – the interface between mainstream and special education is bound to surface again.

Draft article 18 deals with the right to participate in political and public life. Of particular interest are the draft obligations dealing with accessible voting procedures and facilities. Draft article 19 deals with general state obligations dealing with accessibility – broadly understood. Along with the usual obligations dealing with public buildings, there is an interesting obligation to promote universal design. Draft article 19 deals with

personal mobility issues. It contains an obligation to facilitate access by persons with disabilities to high quality mobility aids, devices and assistive technology. Draft article 21 deals with the right to health and rehabilitation. Some objected to the inclusion of rehabilitation. I do not. I think rehabilitation does not exist for its own sake or to enrich the medical profession – it exists as a tool for personal freedom.

Interestingly draft article 22 on the right to work contains references both to quotas and 'reasonable accommodation'. This suits many European countries who traditionally rely on quotas but which now have an additional obligation of 'reasonable accommodation under EU law. Draft articles 23 and 24 deal with the rights to social security and participation in sport and culture.

Draft article 25 deals – or rather does not deal with – monitoring. It leaves open the single biggest issue which has to do with enforcement. Annex II sets out the terms of the debate concerning a possible monitoring body under the treaty. It is obvious that some States do not want a new monitoring body. They would prefer to see monitoring take place within the existing system. I think that would be a disaster. Our Study already demonstrated that this has not worked – where is the guarantee that the existing system would work in the future. The traditional monitoring mechanism envisages an expert body reviewing periodic State reports on progress made and obstacles encountered, etc. I think this is useful. But I would probably lean in favour of allowing for some kind of complaints mechanism.

Usually such complaints mechanisms are optional – that is, if a State wants to opt in it is allowed to do so. My intuition tells me that we should have at least an optional complaints mechanism. It doesn't matter if the majority of States do not sign up to it. The reality is that the complaints will drive forward the understanding of the Monitoring Committee of the obligations which will in turn impact positively on how it reviews the periodic reports of all states.

A secondary issue arises – should the complaints mechanism be confined to groups (e.g., NGOs) or should it be thrown open to individuals. I would tend to favour both. Sometimes NGOs hesitate before tackling Governments. Even when they don't hesitate, it is always good to allow for the raw edges of human experience to be reflected in individual circumstances. I think a treaty would be incomplete without a complaints mechanism.

A related issue has to do with the composition of the Monitoring Body. If this is a human right treaty then the membership should at the very least possess skill and knowledge and experience in the human rights field. That should be a *sine qua non*. But should the treaty exhort States to nominate human rights experts who have particular knowledge or experience of disability? Should a certain number of slots be reserved for persons with disabilities who possess the requisite human right knowledge? Should States be required to nominate a panel of say three, at least one of whom must be a person with a disability? Should the chair always be a person with a disability? I believe so.

Another issue not broached in the draft text is development aid and international co-operation. I strongly believe that States should at the very least have an obligation to proof their existing development aid programmes from a disability perspective. If Irish aid builds schools in Africa then at the very least they should be accessible and all related teacher training programmes should contain mandatory modules on accommodating children with disabilities. I know the World Bank is doing excellent work in the this sphere under the inspired leadership of Judy Hueman. Also, I don't see why States cannot commit themselves to international co-operation in the form of knowledge transfers. It is useful for NGOs in Africa and even in Europe to know how you succeeded in the US. It is useful to learn from each other's mistakes as well as achievements. Both these issues are left to the next Ad Hoc Committee session.

7. Where to Now?

I think such a treaty will not, of itself, lead to immediate change. Rather it should underpin the process of change where it is already happening and will give it some more coherence and direction.

It will also embolden those who are arguing for a process of change where none presently exists. In other words, its mere existence will validate the claims of persons with disabilities and place unresponsive systems on the clear defensive. It should have a clear democratic added value.

It should also enable abuses to be identified and labelled as such. The time for sweeping issues under the carpet is gone – and this treaty could help put an end to that.

It might stimulate the emergence of new kinds of disability NGOs dedicated to the rights of persons with disabilities[38]. And it can have a positive transformative effective on existing NGOs and service providers who might begin to see themselves as allies in the common goal of independence.

I suppose one might call it a Declaration of Independence for persons with disabilities throughout the world. It will signal to the world at large that 600 million persons are subjects and not objects and deserve respect as persons as well as rights holders in common with everyone else on the planet.

I urge you to become engaged and involved.

Most importantly, I urge the United States to become a constructive player in the negotiations for the sake of humanity and on behalf of all those with disabilities throughout the world.

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[38] See, e.g., Disability Rights Promotion International (DPRI), www.yorku.ca/drpi/index.asp