



***Remarks On the Occasion of the United Nations Day of
Disabled Persons***

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1 Introduction.

Today marks the United Nations Day of Persons with Disabilities.

We mark it in a very special building – one that, in its grandeur, reflects both the hopes and highest aspirations of all of mankind. This common yearning is for a world at peace with itself – a world in which the human spirit can flourish in all of its diversity.

Yet today is a day just like any other for the estimated 600 million people with disabilities worldwide. For them, there is little to celebrate and no formal occasion to mark with all the rarefied solemnity that goes with an international event. For generations of persons with disabilities have lived at the edges of society; citizens yes – but invisible citizens nonetheless.

We should do well to remember that the only true grandeur resides within the human soul and that the highest calling of political life is to set that soul free.

The process for drafting a new convention offers hope – hope that has not been evident for quite some time. This is what makes the United Nations, as an institution, inspiring. For the collective conscience of humanity can, on occasion, express itself with clarity and with decisiveness. In this instance it shouts loudly - human rights are for all and *all really means all.*

The next stage in the process involves the convening of a Working Group composed of States and nominees of world disability NGOs to meet here in January. I greatly look forward to the working of the Working Group and trust that further clarity will be added regarding the shape and content of the proposed convention.

It is important to emphasise that a convention would not merely enhance the rights of persons with disabilities but it would also serve the interests of States in that it would add clarity and particularity with respect to their general human rights obligations – obligations to which they are already bound - in the specific context of disability.

The idea of a convention on the rights of persons with disabilities is not new. Great ideas always start with good people. Bob Burgdorf laid the foundations for the Americans with Disabilities Act in his famous blueprint in the 1980s. Likewise, and to their eternal credit, Italy and Sweden early proposed a convention on the rights of persons with disabilities in the mid to late 1980s. Currently, Mexico deserves the highest praise for its vision in grasping this issue as a 21st century global challenge and for ensuring that the issue gets the prominence it deserves on a global scale.

Clearly the idea of a convention is one whose time has well and truly come and the momentum looks both politically and morally unstoppable.

Some will say that the lot of persons with disabilities is inevitable when set against the context of low levels of social development worldwide. Yet, observe the paradox. Even in many countries where social development is high, the status of persons with disabilities does not tend to be correspondingly high. A rising tide will not necessarily lift all boats – especially those that are kept moored to a siding. This is not to say that social development is not important in the context of disability – indeed it is quite crucial. But it is to say that the phenomenon of setting one portion of the population aside needs to be tackled with urgency if social development is ever going to have beneficial effects *for all*.

Some will say that the exclusion of persons with disabilities from the blessings of liberty to which we all aspire is somehow ‘natural’ or ‘inevitable’ in the sense that it results from ‘their’ disability. That is, the problem is the ‘person’ and there is little society can do to fix such problems apart from making them look more like persons without disabilities.

Yet there is nothing natural or neutral about exclusion and discrimination. No one says that it is a woman’s ‘fault’ if she earns less than a man. We all make choices in our lives. Our societies can choose – even in default - whether to make the diversity of the human race a cause for celebration rather than a ground for exclusion. The fact that such choices

are generally made by default makes them all the more difficult to expose and reverse since it becomes all too easy to avoid personal responsibility. Yet, just as we all take credit for the accomplishments of our own communities, so too we must all bear ultimate responsibility for their faults and have enough civic pride to become actively involved in bringing change about.

I can't account for the phenomenon of exclusion or discrimination – nor can I explain why it doesn't even strike the ordinary citizen as exclusion or discrimination. Many such explanatory theories abound. But I do know that it is now coming under sustained attack and not before its time.

Formal rationality alone requires that general principles will inevitably and over time work themselves pure from group to group. Perhaps disability is but the latest example. Perhaps society – including the international society - is slowly coming to terms with the contradiction between its own self-professed values and the status of persons with disabilities. But cold logic alone does not account for the sheer power of the values now driving change.

Hard experience tells us that the exclusion of so many persons from the lifeworld is simply irrational. Put positively, the liberation of persons with disabilities is a productive factor in any rational economy. Yet it must also be insisted that the exclusion of persons with disabilities jars our moral conscience – it is not merely wrong because it is irrational; it is simply wrong. Put positively, the liberation of persons with disabilities is also a civilising factor in any democratic society worthy of the name. And human rights are key carriers of this vision of inclusion and humanity.

2. The Values of Human Rights – Confronting the Ethic of Exclusion.

I think it is clear by now that the worldwide process of disability reform has been driven by these two related insights; that inclusion is both a productive factor as well as a civilising factor.

These influences are evident in the recent explosion in comparative disability law ranging from the United States to Hong Kong, Mexico, Hungary, South Africa and Ireland to name a very few. Indeed, many treaty monitoring bodies – whether global or regional - now pay greater heed to the challenges involved in making freedom real for persons with disabilities. Issues and cases are beginning to emerge before these bodies and they are beginning to respond appropriately.

Its easy to see why they should. Stripped of technocratic pretension, human rights derive their potency and resonance with the human spirit from a series of related basic human values. Human rights help us to see reality in a different way, they help us to form clear judgments about that reality and they help guide us in brining about a better world for all. That why the shift to the human right paradigm is so powerful in the context of disability.

Take the foundational value of human dignity. Despite the weight of history, it insists on the inherent self-worth of all human beings regardless of their differences. But how quickly it is that we tend to value people for their use-value rather than for who they are! How quickly we forget those who are not useful (or, to be more accurate, who are not judged to be useful) and then consign them to the margins of society or left incommunicado in institutions on the margins.

I believe that the process of drafting a convention should serve to jolt us into truly accepting – and not just rhetorically - the self-evident proposition that there are no insignificant persons in the human race. There is only willful blindness to their plight.

Take the ethic of human equality. It insists that all persons are of equal inherent worth and that power –especially public power – should respond appropriately and respectfully to relevant differences. Modern non-discrimination law is keenly alive to the need to

ignore difference where required, and ,to positively accommodate it when needed to make equality real and not just illusory. Equal treatment is not just about refraining from certain action; it also entails engaging in action to create space for difference. Yet achieving equal opportunities for persons with disabilities remains a distant dream for most.

I believe that the convention should serve to underline the importance of securing the equal effective enjoyment of all human rights for persons with disabilities. I think a strong and clear message should emerge from the eventual text – one that commands the moral and political authority of the broad international community – that the doctrine of ‘separate but equal’ that has given rise to so much unnecessary segregation has no place in modern human rights law and especially in the context of disability.

Take the value of autonomy. It means as it says – self-government or self-determination. But is often feels as if society is making judgments about the inherent worth of ‘selves’ and effectively denying self-determination to those who appear to need it most and in contexts where the limitations fall heavily. We need to get serious about the role of human rights in restoring power to people over their own lives.

I believe that the core value of self-determination and the related concept of independent living to which it gives rise in the disability context should rank very high indeed in the scheme of values to be reflected in and advanced by the convention.

Take the value of solidarity – the idea that we are not exclusively self-regarding atoms but that we owe something to each other, that your fate is intimately tied to mine fate and that we cannot afford to ignore the plight of others. We are drawn to each other in a mutual bond of humanity. How amazing it is then, that our welfare systems – systems that owe their very existence to the ethic of solidarity - often seem more interested in passively maintaining people with disabilities than in freeing them up for a life of involvement and commitment. Clearly our welfare systems need substantial re-

engineering to make them into agents of liberation rather than sources of compensation for exclusion.

I believe the convention should play a crucial role in ensuring the economic and social supports are harnessed to enhance liberty and support freedom and choice.

3. Human Rights and Public Freedom.

The famous German philosopher, Jurgen Habermas, once wrote that human rights are not primarily about things that people have – rather, they express ideal relationships between persons. Up to now that relationship in the disability context has been marked by exclusion and discrimination.

Modern human rights law is not only about shining a light in dark places and protecting people against power – it is also about restoring power to people over their own lives. Furthermore, human rights is not merely about protecting individuals in their social isolation – it is also about forging pathways into the community for a life of participation and active involvement. In a strange way, it is as if we are reverting to the great Greek idea that true freedom is public freedom which was the freedom to belong and to participate.

4. The Added-Value of the Convention.

I mentioned earlier that the existing treaty monitoring bodies are beginning to become alive to disability as a human rights issue. If so, do we need a new convention? This is a good question and requires a clear answer.

Firstly, it has to be realized that the existing treaty bodies are drawn in many different directions by pressing problems that won't go away and which rightly demand their attention. There would appear to be little chance of getting them to focus in a sustained way on the issue of disability. This is not at all a criticism of the existing system. But it

is to say that unless deliberative space is carved out for the disability issue it is unlikely to get the attention it deserves at the very highest levels. It was for exactly these kinds of reasons that the other thematic conventions were drafted.

Secondly, the addition of a new thematic treaty should enable the relevant treaty monitoring body to develop the necessary insight and expertise which should help to ratchet upwards the level of understanding of the main treaty bodies on disability. The general human rights provisions contained in the two headline Covenants resonate in the field of disability – but their resonance is unfocused precisely because their very generality does not allow for any calibration with the specific circumstances of persons with disabilities. Unless this conscious tailoring of the general rights to mesh with the particular circumstances of persons with disabilities occurs, then the full import of the general rights norms is unlikely to fully materialise in the disability field.

Thirdly, it must also be realised that disability NGOs are amongst the poorest of the poor. Although they have been making great strides in a relatively short space of time, and with some notable exceptions, they are still not sufficiently tooled up to make maximum use of the existing machinery. The synergies that should emerge with the interaction of disability NGOs with more mainstream human rights NGOs are still some distance away. If, however, all the relevant normative benchmarks were drawn together in one composite thematic convention this would provide added incentives for disability NGOs to engage with the system. Such engagement would help to enrich, clarify and develop the jurisprudence – to the mutual advantage of States and persons alike. No one doubts the beneficial effects of the Convention on the Right of the Child or CEDAW in this respect.

A disability convention is not an end in itself. It is a means – perhaps an indispensable means – toward the higher end of underpinning positive change where it occurs and stimulating democratic reforms where such stimulation is required.

I believe the leitmotiv of the convention should be the urgency of securing the equal effective enjoyment of all human rights for persons with disabilities. My own personal view is that the monitoring/complaints mechanism will be crucial. Responding to periodic reports is one thing. Being confronted with the raw edges of human experience in the form of a complaint (whether collective or individual) is quite another. In the face of such challenges it is hard to avoid the necessity for depth analysis and for jurisprudential advances where they are genuinely called for.

I am also personally attracted to the idea of requiring States Parties to proof their development aid programme to ensure that, at the very least, it does not compound the isolation of persons with disabilities and which can, at best, can be leveraged to ensure that societies develop on an inclusive basis. Coming from a country with a highly developed development aid programme, I know just how potent these programmes can be lifting people out of cycles of dependency and into a life of independence.

5. Conclusion.

Eleanor Roosevelt – one of the architects of the Universal Declaration of Human Rights once asked where do human rights begin. Her answer was revealing She said

[Human rights begin]...In small places, close to home – so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighbourhood he lives in; the school or college he attends; the factory, farm or office where he works¹.

She was right. She might have mentioned schools, hospitals, mental and other residential institutions and rehab centres. A convention will ultimately be judged on whether it reaches into small places – all the places where people ordinarily live, work and interact. Potentially it should help bring about a sea change in attitudes in small places. Potentially it should open up small places to everybody. A convention is not a panacea. But it can and should be an indispensable catalyst for change.

¹ Quoted in Mary Ann Glendon, **A World Made New: Eleanor Roosevelt and the Universal Declaration of Human Rights**, (Random, 2001), at 239-240.