

A Review of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1994, United Nations Department for Policy Coordination and Sustainable Development

by Raymond Lemay

The "raison d'être" of the "Beyond Normalization: Towards One Society For All" conference (Reykjavik, June 1994), which led the United Nations to sponsor the event, was the presentation of the "Standard Rules" (SR) by representatives of the United Nations. There is no doubt that this is an important text and that it should be read. Representatives from many countries, both developing and developed, after a great deal of lobbying and pencil-sharpening, have come up with a 41-page text that contains the present international consensus—at least from amongst the disability elites—on what is to be done for Disabled Persons.

The SR were presented and discussed at a number of plenary sessions at the Reykjavik conference. The presentations were formal with various members of the Working Group which drafted the SR making speeches about their implications. When questions or comments came from the floor, they were usually from people who were on a first name basis with the folks who were presenting, giving the impression that an inner circle of SR contributors were present to discuss but especially celebrate their advent. There was really very little debate about the substance of the SR, but rather about the implementation and especially the monitoring thereof. The rest of us were mostly witnesses to what was described to us as an historic event.

In the first part of this review, I will spend some time presenting the text in order to give you a flavor of what it contains. In the second part, I will present some very preliminary observations and comments on what was achieved in the text and on some obvious shortcomings.

A Review of the Standard Rules

The Standard Rules were adopted by the United Nations General Assembly on December 20th, 1993. This text grew out of the work done by

various committees of the United Nations during United Nations decade of Disabled Persons, from 1983 to 1992. Initially, it had been the ambition of those on the special working group to prepare an international convention aimed at the "elimination of all forms of discrimination against persons with disabilities" (page 6), but they were unable to convince their political masters of the need to do so; "in the opinion of many representatives, existing human rights documents seem to guarantee persons with disabilities the same rights as other persons" (page 7). Thus, they came up with the notion of developing Standard Rules that would not require ratification by individual states but could be useful nonetheless. "Although the Rules are not compulsory, they can become international customary rules when they are applied by a great number of states with the intention of respecting a rule in international law. They imply a strong moral and political commitment on behalf of States to take action for the equalization of opportunities for persons with disabilities" (page 8).

Simply stated, "the purpose of the Rules is to ensure that girls, boys, women and men with disabilities, as members of their societies, may exercise the same rights and obligations as others" (page 8).

The document is built on terminology that had been approved by the World Health Organization in 1980, which brought forward a classification of "impairments, disabilities and handicaps." Though these distinctions are made at the beginning, it is hard to see where they are applied elsewhere in the text. The fact that a United Nations working group appears to have found little use for these distinctions in their own text is somewhat telling. By and large, the text uses the expression "person with disabilities" as being the focus of all the Rules. "Impairment" and "handicap" are almost nowhere to be seen.

At the outset, there are definitions of prevention and rehabilitation. Many people will be reassured by a very positive definition of prevention that does not in any way state or even hint at the elimination of persons who are disabled, as by abortion.

The ideological underpinnings of the Standard Rules are contained in the notion of equalization of opportunities. It is this principle, if you will, that is proposed to replace the prehistoric (I refer here to the conference title) notions of integration and normalization which are mentioned only once in the introduction (article 4). Since the principle of equalization of opportunities is the foundation of the whole text, I thought it would be well worth reproducing in whole the four relevant articles that define equalization of opportunities.

- *"24) The term "equalization of opportunities" means the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all, particularly to persons with disabilities.*
- *"25) The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation.*
- *"26) Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services.*
- *"27) As persons with disabilities achieve equal rights, they should also have equal obligations. As those rights are being achieved, societies should raise their expectations of persons with disabilities. As part of the process of equal opportunities, provision should be made to assist persons with disabilities to assume their full responsibility as members of society" (pages 11 and 12).*

The text then goes on to list the Standard Rules themselves. There are in all 22 rules and some 128 subrules.

The Rules are divided into three broad sections. The first, "preconditions for equal participation" groups together four rules, including rule 1, "awareness raising"; rule 2, "medical care"; rule 3, "rehabilitation"; and rule 4, "support services."

The second cluster of rules is contained under the title "target areas for equal participation" and it includes, rule 5, "accessibility"; rule 6, "education"; rule 7, "employment"; rule 8, "income maintenance and social security"; rule 9, "family life and personal integrity"; rule 10, "culture"; rule 11, "recreation and sports"; and rule 12, "religion."

A third cluster of rules is contained under the title "implementation measures," and includes rule 13, "information and research"; rule 14, "policy-making and planning"; rule 15, "legislation"; rule 16, "economic policies"; rule 17, "coordination of work"; rule 18, "organizations of persons with disabilities"; rule 19, "personnel training"; rule 20, "national monitoring and evaluation of disability programmes in the implementation of the rules"; rule 21, "technical and economic cooperation"; and rule 22, "international cooperation."

A fourth section contains thirteen articles that provide for an international monitoring mechanism. These last articles set-up the office of a "Special Rapporteur" and the creation of a "panel of experts," both of which have advisory and fact-finding functions. It was this last section, as well as rule 20, which were the most hotly debated topics during the conference plenary sessions.

We should be pleased, of course, that the first rule is one of awareness raising. "States should take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution" (page 17). But only one of the nine subrules is concerned with imagery; "states should encourage the portrayal of persons with disabilities by the mass media in a positive way" (page 17). All the other subrules are interested in the notion of information sharing: on the one hand, about persons with disabilities, their rights and their needs, and so on, and on the other hand, about the need for sharing information on available programs, etc.

Rule 4, on support services, deals mostly with assistive devices and technological supports. There are two subrules on personal supports and these are to be mediated through paid services.

Accessibility is defined as accessibility to the physical environment and accessibility to information and communication. Special provision is made for the use of sign language. Subrule 7 states "consideration should be given to the use of sign language in the education of deaf children, in their families and communities. Sign language interpretation services should also be provided to facilitate the communication between deaf persons and others" (page 23).

Education is promoted within integrated settings and "in states where education is compulsory, it should be provided to girls and boys with all kinds and all levels of disabilities, including the most severe" (page 24).

In terms of employment, "the aim should always be for persons with disabilities to obtain employment in the open labour market. For persons with disabilities whose needs cannot be met in open employment, small units of sheltered or supported employment may be an alternative" (page 26). In rule 9, for family life and personal integrity, we are told that the state "should promote the full participation of persons with disabilities in family life" (page 28). In this rule, we find the only reference to the negative attitudes that people in society might hold towards persons with disabilities, and this is in subrule 3 when reference is made to marriage, sexuality and parenthood of persons with disabilities. "The media should be encouraged to play an important role in removing such negative attitude" (page 28).

As for the Rules that are concerned with implementing the equalization of opportunities, these generally state that the government of each country is responsible to ensure that all of these good things happen, that they should remove barriers and promote equalization of opportunity and ensure that disabled persons participate in the implementation.

Some Comments on the Standard Rules

First, I am in no position to comment on the legal value of the Standard Rules and whether

or not they really will have any impact on government activity for devalued persons. But I do get the sense that if a first world government took these rules seriously, there could be a marked improvement in the life situations of many devalued persons. Having said that and having reviewed the text, one sees some obvious limitations that should make one wary of jumping on any bandwagon about the construction of government action based on the Standard Rules. Simply put, there are better blueprints around.

1) Beyond Normalization?

The principle of "equalization of opportunities" is fairly simpleminded and even problematic. Article 25, about equal rights and equal importance, is not a good way of ensuring that individuals with greater needs will get the resources they require to be able to participate in society. It is certainly not the measure of the conservatism corollary that one finds in SRV. Though here and there we find the concept of "full participation" listed as a goal for this or that rule, it is never defined. One gets a sense that the SR are concerned primarily with the notion of physical integration and nothing more. Throughout the text what we see is technological support, professional service, access to places and information, but never do we see the people whom disabled persons will have to mingle and live with. The notion of "ordinary structures" (article 26) is very similar to the now over 25 year old proposal to use generic services. The ubiquitous notions of equal rights and equal responsibilities are accompanied by a seeming inversion of the dynamic of expectations where expectations are increased following the achievement of equal rights.

Except for the expression "full participation," one gets no sense of how the SR will translate into the day to day reality of social coexistence. As we have known for a long time, physical integration might be a necessary precondition for social integration but it is certainly not sufficient. Equalization of opportunities as defined in the SR could lead disabled persons to live lives in parallel to those of other community members. The only place where we get a sense that they have greater ambitions is in the rule for education. But here again, the SR are concerned with integrated settings; nowhere are the other children in the schools mentioned. The SR are really only a list

of preconditions enabling governments to facilitate the occurrence of physical integration.

2) Third World Realities

It is hard to imagine that Third World representatives were involved with the drafting of the Standard Rules. I can see how all these rules and subrules could be relevant to countries like Canada, Australia, countries in western Europe, or the United States; most of the rules assume a high level of service sophistication, bureaucratic structures and most importantly money. Many of the proposed fixes are technological, all of the personal service is professional, or para-professional and all of the rules require highly sophisticated service systems. It is hard to imagine how a country that is based on a subsistence economy could even think of implementing any of these rules.

During the conference, we were shown an interesting home video about physically handicapped people in Romania. One part of the video showed how the Romanian government had invested in the development of gasoline engine-powered wheelchairs, but then made it next to impossible for physically handicapped people to buy the petrol required to make their wheelchairs run. Romania, though in dire straits, is not a developing country, and yet, based on that 30-minute video, it would be hard for me to imagine how the SR are in any way relevant to the plight of Romanian disabled persons.

3) Top-Down Reforms

A fundamental concern that comes out through the text is that it invests national authorities with the first and ultimate responsibility for the plight of Disabled Persons. These are top-down reforms. In all the Rules, one reads "states should" and "states shall." Thus, disabled persons are not the people of the community, they are the people of the state. There is an attempt at a disclaimer of sorts in rule 14 where subrule 4 states that "the ultimate responsibility of States for the situation of persons with disabilities does not relieve others of their responsibility" (page 32). These Standard Rules purposely take away the responsibility for devalued people from the community, local government, family, religious congregations, etc., to give it to the national authorities.

This does explain, however, the great absence of notions such as community, social integration and the lack of a sense of where common folk fit in. The reason for this absence is very simple. The elite that drafted the Standard Rules appear to have a profound mistrust and even distaste for the community and for the idea of local government. This is the message between the lines of the text, if you will, and it was made quite evident at the plenary sessions in Reykjavik. Time after time, members of the UN inner circle would get up to ask how "we" could trust local authorities and communities to implement the legislation that would come from the SR without subverting their intent and spirit. Time after time, the answer was that national authorities would have to draft and impose unequivocal and very directive legislation.

This is a similar phenomenon to what we have witnessed in Canada where over the past 30 years since the second World War, provincial and federal governments have continuously removed responsibilities from local governments, in part because of what we might call the "redneck" factor (rednecks are people whose necks are sunburnt because of manual labour, and they are usually portrayed as being intolerant, bigoted and unsophisticated). Many legislators, bureaucrats and public policy-writers start with the premise that the kindness of a society is to be found in state government and that there is no compassion in the community. Now, of course, this is problematic because people don't live in government offices or in state legislatures, they live in the community. Social integration and the attribution or crafting of valued social roles happens when the majority mingle and mix with the minority or devalued and handicapped. Clearly, the starting premise of the Standard Rules is that this won't occur unless it is forced to happen. Now, of course, taking away responsibility means making people irresponsible. Will the implementation of the SR through government legislation mean that the community will follow gladly, or is it the prelude to a backlash? Moreover, the nation-states that the United Nations deals with and that the working group wants to invest with so much authority to implement the Standard Rules are the same folks that bring us war, famine, genocide and corruption. These are the people who don't trust the community!

Conclusion

People at the conference, at least the "UN types," took the Standard Rules very seriously, and there is no doubt that at least symbolically, it is quite a testament that such a diverse grouping could come up with a text that does contain some fine things. If the SR get broad dissemination, this could be of value as a consciousness-raising tool, mostly for politicians and policy-makers. Thankfully, a few panelists did mention the fact that new laws and new rules could not make a material difference if there was not a concomitant ideological commitment to provide the enabling financial resources.

But by and large, one got the impression that many of the persons in the audience as well as most of the members of the UN inner circle were quite convinced that the political class that makes up the UN and most national governments had this problem well in hand, and would be able to make some dramatic inroads around the world toward improving the life situations of handicapped persons—this, despite the fact that the newspapers and TV news are full of reports of the UN's incapacity to maintain the peace in Bosnia, Somalia and so many other places in the world, monitor North Korea's evolving new nuclear program, establish acceptable human rights practices in many countries, enforce blockades to countries that are at odds with the UN requirements, and so on. Martin Söder of Sweden commented that he was quite surprised at the naiveté of so many people who put their faith in the possibility that actions of the UN could accomplish from afar and for the whole world what we can hardly accomplish in our own communities and neighborhoods.

The UN has set up a monitoring program that is to be led by a very kindly Swedish gentleman by the name of Bengt Lindquist who spoke a number of times at the conference. Many persons doubted that the monitoring agency would have any teeth or would have sufficient resources to truly monitor what was going on around the world. Some members of the audience suggested that the UN always had enough money for peacekeeping and armed intervention, but never had any money for the handicapped. This generated resounding applause from the audience. I guess persons didn't really consider the implications of this comment. On the one hand, if the UN was to pull out of Bosnia, say, so

that it could do a better monitoring job, there is a possibility that it would lead to an even greater bloodbath that would not only kill many ordinary valued citizens of those communities, but also handicapped persons. Moreover, in the past few years, the UN has protected the International Red Cross when it has gone into Bosnia and other parts of Yugoslavia to save literally hundreds of handicapped persons who had been left to die of starvation in a number of Yugoslavian institutions. There is only so much you can do from the top and there would, of course, be a price to pay for such ideas.

There is another wrinkle to this, and that is, of course, the United Nations is so deeply in debt at the moment, and many countries (who would be called upon to implement the SR) owe literally billions of U.S. dollars to the United Nations as they are in arrears on membership fees. Clearly, the United Nations is already overextended and unable to meet its present commitments, let alone take on new ones.

The UN monitor could consider conducting, on a regular basis, complete PASSING evaluations of each country that endorses the standard rules. One of the UN representatives suggested that there should be interesting contests between countries on how well they perform vis-à-vis the standard rules, and since an annual report will be published country by country, this will lead to some healthy competitions between heads of state. Of course, we all know how well this reality operates in the agency world! Agency directors don't really want to know how well they're doing on quality measures and are even less ready, more often than not, to allow any type of comparison to like agencies.

Finally, though the UN as a symbol is very heartening, the reality of its accomplishments makes this endeavor into the field of handicap and disabilities less than promising.

You can get more information concerning the Standard Rules by writing to:

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