

QUARTERLY - WINTER 1995 - No. 6

HELIOSCOPE



the UN Standard Rules

on the Equalisation of Opportunities for Persons with Disabilities:
a policy instrument for the European Union?

EUROPEAN DISABILITY MAGAZINE

e d i t o r i a l

Bengt Lindqvist

*UN Special Rapporteur
of the Commission for Social
Development on Disability*



Europe should take the lead

“In all societies of the world there are still obstacles preventing persons with disabilities from exercising their rights and freedoms and making it difficult for them to participate fully in the activities of their societies.”

This is a quotation from the latest text in the disability field, entitled Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. The unanimous adoption by the United Nations General Assembly of this new instrument must be considered a major event in the development of a modern international disability policy. But what is the background and the rationale behind it?

As you all know, 1981 was the UN International Year of Disabled Persons. The theme of the year was full participation and equality. As a result of the year, the General Assembly of the UN adopted the World Programme of Action concerning Disabled Persons in 1982. Those events were, of course, historical cornerstones in the disability field. They signalled worldwide recognition of the basic human right to participation for disabled people. Disabled people are citizens of their societies like anyone else and have the same right to participate in the activities and development of their societies. All obstacles to such participation should be eliminated.

Naturally, this message from the highest international assembly created great expectations among disabled people the world over and kindled dreams and visions of a society designed to meet the needs of all its citizens. The implementation of the measures and programmes in accordance with this new policy was to take place during the International Decade of Disabled Persons (1983-1992). Although many positive initiatives were taken during that period, far too little was achieved. Halfway into the decade, therefore, the interna-

tional disability community started to request stronger leadership from the UN in the implementation of the measures suggested in the world programme of action. In response to this request and in order to speed up the implementation work, the UN decided to develop a new instrument containing more concrete and precise guidelines for national action. That is how the standard rules came into existence, and it is very important to understand their background.

The standard rules were adopted by the General Assembly in December 1993. More than 70 government delegations and all the major organisations in the disability field had participated in drafting them. In the resolution which introduced the standard rules to the General Assembly for adoption, all member States were urged to participate actively in a global effort to improve the living conditions of disabled people and to increase their opportunities for active participation in society. It is therefore fair to say that all nations, including the members of the European Union, are both morally and politically strongly committed to take action in accordance with the guidelines set out in the rules. In my opinion, disabled people the world over have a right to expect their governments to take active and concrete steps now to implement the guidelines set out in the standard rules.

In my work as Special Rapporteur for the implementation of the standard rules I have encountered widely varying attitudes on the part of government representatives. In some countries a new dialogue has been launched between the gov-

Letter from the Editor

In devoting this issue to the United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities we are seeking to promote debate on the desirability of including an anti-discrimination clause in the EU treaty.

Whatever the outcome of the 1996 intergovernmental conference on reviewing the treaty, debate in society will, in the intervening period, heighten general public awareness of the legitimate demands of disabled people. The debate also gives hope to the disabled community and provides support for all those who are committed to giving disabled people maximum scope for development and to reforming structures which stand in the way of equal opportunities. We shall return to this subject in a later issue of *HELIOSCOPE*, in the light of ongoing preparations for the intergovernmental conference.

Philippe Lamoral
Director
HELIOS Team of Experts

ernment and the organised disability movement. This is excellent. I have, however, also observed a tendency towards complacency among representatives of governments who have achieved a lot in the disability field, and that is deplorable. There is no room for complacency anywhere regarding the situation of disabled people. As the opening quotation states, there are still obstacles to full participation in all countries of the world, and as long as these obstacles exist we have to keep developing and refining measures to achieve higher levels of participation.

The standard rules document provides for an initial monitoring period of three years (from 1994 to 1997). As Special Rapporteur I have chief responsibility for the monitoring exercise. I cordially invite the governments of all Member States of the European Union to participate actively in our global implementation effort. I also welcome the current debate within the European Union on joint measures to encourage and support implementation initiatives in each Member State. I sincerely hope that I will be able to report strong and determined action from the European Union and its Member States when I write my final report to the General Assembly of the United Nations in early 1997. There is even time enough for Europe to take a lead on this important social issue.

Feature

► The UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities*

Historical background	4
From objects of charity to subjects of civil rights	7

► Putting words into action: the value of the standard rules for the European Union

Legislation (Rule 15)	10
Coordination of work (Rule 17)	12
NGOs (Rule 18)	13
Accessibility (Rule 5)	14
Education (Rule 6)	16
Employment (Rule 7)	18

► The standard rules as a policy instrument:

At European level	20
At national level	22
At grassroots level	23

European Parliament

The Disability Intergroup	24
---------------------------	----

* NB: abbreviated in most cases here to "UN standard rules"

In the next issue

The impact of new technologies

CEE:V/102



Historical

the **UN Standard Rules** on the Equalisation of Opportunities for Persons with Disabilities

The genesis of the standard rules goes back to 1981, the UN's International Year of Disabled Persons, when the activities of the various international disability organisations, and of course the UN itself, came into the limelight.

The main result of the latter's work was the drafting of two key declarations – the Declaration on the Rights of Mentally Retarded Persons in 1971 and the Declaration on the Rights of Disabled Persons in 1975 – and the designation of the period 1983-1992 as the Decade of Disabled Persons. What was new about the declarations was that they explicitly invoked the Universal Declaration of Human Rights as a normative framework applicable to the disability sector and upheld disabled people's rights in a number of areas, particularly in social, family and professional life, social security and other limited fields. Thus the rights enshrined in the 1971 and 1975 declarations did not include a number of those conferred upon non-disabled people under the universal declaration and the instruments deriving from it (e.g. the United Nations Covenant on Economic, Social and Cultural Rights and the 1966 International Covenant on Civil and Political Rights), instead giving prominence chiefly to rights in the health and social fields. Moreover, the prevailing approach to disability, both at international level and within individual countries, remained one of charity rather than solidarity. At that time

a terminological debate was emerging at all levels and in all spheres – national and international, governmental and non-governmental – on the relative merits of the terms “handicap” (which carries the negative connotation of the obstacles society places in the way of all those people in temporary or permanent difficulty owing to genetic or other causes) and “disability” (or disablement). This debate was conducted mainly within the World Health Organisation, which set out to determine the meaning of the term “disability”, without attempting to impose one or other expression in any language. (It is common knowledge, for example, that the term “handicapé” continues to be used in French.)

Furthermore, the World Programme of Action concerning Disabled Persons subsequently put forward by the United Nations and adopted by the General Assembly in Resolution 37/52 on 3 December 1982 went further than the declarations, listing a range of areas which had previously been neglected. Besides, of course, discussing the issue of rehabilitation, the programme enshrined the principle of equal opportunities not only in the field of health,

After the concept of non-discrimination came recognition of the fact that disabled people are, in general, citizens of their countries and, as such, should enjoy all the rights attendant upon citizenship.



background:

education and work, but also as regards recreation, religion, culture and sport, upholding disabled people's right to access to the physical environment through the removal of architectural and, particularly with regard to people with mental health problems, cultural barriers. Nevertheless, the connection between human rights and disability seemed to remain more a declaration of principle than a reality or, better, a legislative goal. Article 163 et seq. of the world programme did make explicit reference to human rights, recalling the theme of the International Year of Disabled Persons ("full participation and equality"), but made no further substantive progress on the issue, beyond exhorting the Economic and Social Council's working group entrusted with the examination of reports under the International Covenant on Economic, Social and Cultural Rights and the Commission on Human Rights, which has the function of examining reports under the International Covenant on Civil and Political Rights, to pay "due attention" to the application of the covenants to the situation of disabled people. Moreover, the scope of the programme was such that referral to the working group (since dissolved) and the commission was the only means of monitoring disabled people's exercise of their human rights.

Intensive research into human rights over the period 1970 to 1980 in particular led us to develop – with reference to the broader issue of human rights – two principles which have since gained general acceptance: firstly that intervention in the internal affairs of individual States must be an option, and secondly that the principle of non-discrimination, the vital premise underpinning the principle of equal opportunities, must be upheld with regard to the situation of specific individuals (women, men, foreigners and nationals, disabled people, refugees and elderly people). This conclusion was the result of analysis of the situation of each group to determine the common denominator – which was revealed to be precisely the principle of non-discrimination. To clarify this concept we should note that a provision in national or international law which discriminates against an individual on gender-related or other grounds by denying a given right blocks all normative

moves to change the status quo, including positive action (by which we mean positive action aimed at achieving an improvement, if only temporarily, in a subjective condition, insofar as it is possible and desirable and insofar as there are no obstacles in principle at prescriptive level). After the concept of non-discrimination came recognition of the fact that disabled people are, in general, citizens of their countries and, as such, should enjoy all the rights attendant upon citizenship, over and above those to which they are entitled by virtue of their special circumstances under appropriate special measures of a temporary nature (positive action).

Asserting such principles in Italy and abroad was no easy matter. It required not only a new approach to a problem which had hitherto been sidelined in favour of other issues felt to be of greater social impor-

tance, but also a new way of thinking – viewing and resolving disability issues not on the basis of charitable principles as had previously been the case, but by invoking the rights which are every human being's due. This school of thought, which was seen at the time as innovative and attracted considerable attention from the United Nations and governments as well as non-governmental organisations, faced opposition from none other than Article 1 of the Universal Declaration of Human Rights, a document whose importance as a set of "cogent international provisions (jus cogens)" we had long stressed in our research. Article 1 states that all human beings are born free and equal in dignity and rights. However, imbued with the Gallic rationalism of the Enlightenment, it goes on to say that "they are endowed with reason and conscience and should act towards one another in a spirit of brotherhood". It is true that this assertion – which would otherwise have deprived people with mental health problems of their human rights (this is where the con-

For a long time, the connection between human rights and disability seemed to remain more a declaration of principle than a reality or, better, a legislative goal.



The principle of non-discrimination, the vital premise underpinning the principle of equal opportunities, must be upheld with regard to the situation of specific individuals (women, men, foreigners and nationals, disabled people, refugees and elderly people).

cept of discrimination comes in) – is tempered by Article 2, which acknowledges that the rights set forth in the declaration apply to everyone “without distinction of any kind, such as race,... birth or other status”. Thus Article 2 restores, in theory at least, the rights which, under Article 1, are seen to apply only to individuals endowed with “reason and conscience”, to everyone without discrimination.

Nonetheless, to sum up a lengthy historical and legal process, it should be noted that, at the United Nations meeting of experts for the European region held in Ljubljana from 10 to 13 March 1987, we proposed, in our capacity as expert for the Italian government, investigating the possibility of concluding an international convention by the end of the Decade of Disabled Persons. This was to be a binding international agreement on eliminating discrimination against disabled people, following the legal precedents created in relation to the rights of other groups – women and children in particular – which were to culminate in the 1979 and 1989 conventions respectively (the latter being at the negotiating stage at that time). The meeting unanimously accepted the proposal, which we reformulated at the world meeting of the 25 UN experts, held in Stockholm from 17 to 22 August of the same year. It again received unanimous approval and was included in the conference’s final resolution. At the 42nd session of the United Nations General Assembly, Italy publicly called upon UN member States to conclude an international convention on the elimination of discrimination against disabled people, and presented a draft outline of the text. Considerations of a financial nature, relating to increases in the UN’s expenses and responsibility, and concerns that it would be “inappropriate” to set up a special international instrument for disabled people, caused the project to be shelved. The matter was subsequently raised once more by Sweden, finally resulting not in an international convention, but in a set of “Standard Rules on the Equalisation of Opportunities for Persons with Disabilities”. In a working document prepared at the UN-sponsored conference held in Helsinki from 7 to 11 May 1990, we stated that “although the standard rules are not mandatory, they could acquire binding force if observed as a matter of custom in a significant number of States”. These principles were enshrined in points 13, 14 and 15 of the rules as adopted by the General Assembly of the United Na-

tions in its Resolution 48/96 on 20 December 1993. The working document also suggested that it would be appropriate to set up a monitoring mechanism – something never before attempted for any other set of standard rules – to review the application of the rules by the member States. The appointment of a United Nations Special Rapporteur, in the person of Bengt Lindqvist, who is also authorised to liaise with NGOs to monitor the application of the provisions, is extremely important in giving the rules further “legal effect”. This overview would not be complete without a mention of the Vienna Declaration and Programme of Action adopted at the UN’s World Conference on Human Rights in Vienna in June 1993, which reaffirm that “all human rights and fundamental freedoms are universal and thus unreservedly include persons with disabilities...” – a resounding acclamation of a principle on whose effective implementation may in part depend the destiny and status of over half a billion people throughout the world.

Maria Rita Saulle

*Director of advanced studies
in the international protection
of fundamental rights
University of Rome – La Sapienza
Italian government
delegate on disability issues
to the Ljubljana and Helsinki
conferences and sessions of the
UN General Assembly
Viale Aeronautica 61
I-00144 Roma*



From objects of charity to subjects of civil rights

The international disability movement has been called “the last civil rights movement”. Civil rights movements are social groups whose members have experienced oppression, exclusion and other forms of discrimination over a long period of time. Like other civil rights movements, the disability movement was born when disabled people became aware of infringements of their human rights, organised and spoke up for themselves at local, national and international level.

Disabled people began to see their disability in the same political context as black people view their “race” and feminists their gender. In particular, segregation and institutionalisation, which have been part of disability policy for so long, were seen in the same context as racial segregation and apartheid. Disability was reconceptualised as a different state of being rather than a tragic deviation from “normality”. On the basis of this social concept of disability, disabled people started to demand fundamental human rights, such as equality and protection against discrimination.

Like other civil rights movements, the disability community learned to work with governments who are responsible for human rights violations, and to use the law as a tool to fight for their rights. It is in this historical and political context that the United Nations’ new Standard Rules on the Equalisation of Opportunities for Persons with Disabilities must be seen. Like the UN report on human rights and disability which was finalised two years before in 1991, the standard rules mark a milestone in the recognition of disabled people’s claim to human rights. During the United Nations’ Decade of Disabled Persons, the defining concept of international disability policy slowly changed from goodwill to human rights. Because disabled people were represented by strong and radical NGOs, notably DPI (Disabled Peoples’ International), at the United Nations, the international disability movement had a strong impact on both the human rights report and the standard rules. The language of these documents reflects the spirit and philosophy of the movement.

The 22 standard rules reflect the demands of the international disability movement and, most importantly, paragraphs 24-27 of the introduction contain an equality concept that goes beyond those incorporated in other United Nations human rights instruments. The concept of equality laid down in the rules rejects not only direct and open forms of disability-based discrimination, but also those relatively subtle forms which may be summed up as the denial of reasonable accommodation. The most famous example of the denial of reasonable accommodation is the case of the school director who denies access to disabled students by keeping the premises architecturally inaccessible. The standard rules emphasise that “the needs of each and every individual are of equal importance...”

There are, however, also some shortcomings in the rules. Most importantly, they are not binding in international law because they are not a treaty. Proposals for the adoption of a draft Convention on the Elimination of All Forms of Discrimination Against Disabled Persons were rejected by the UN General Assembly at the end of the International Decade of Disabled Persons. The standard rules were adopted as a substitute, and this means that, while the disabled community constitutes the largest minority worldwide, we find ourselves at a disadvantage in relation to other vulnerable groups in that there is to date no binding human rights instrument which explicitly protects our human rights. But this regrettable legal situation should not prevent us from using the rules. Instead we should make them a tool for achieving greater human rights protection in the future.

Like other civil rights movements, the disability community has learned to work with governments who are responsible for human rights violations, and to use the law as a tool to fight for their rights. It is in this

historical and political context that the United Nations' new Standard Rules on the Equalisation of Opportunities for Persons with Disabilities must be seen.

The standard rules were not the first human rights instrument explicitly for disabled people and they will not be the last. Since the 22 rules have a strong bias towards regulation in the field of economic, social and cultural rights, other legal instruments are needed. Other human rights violations mentioned in the Despouy report (*), such as female circumcision, enforced sterilisation, human rights violations occurring during armed conflicts, and other forms of cruel and degrading treatment in the context of certain forms of punishment and scientific experimentation must also be addressed by human rights law.

In contrast to the United Nations, European organisations, notably the Council of Europe and the European Union, have been less forthcoming on the issue of disability and human rights. Their involvement commonly confines itself to the areas of rehabilitation and health and to the economic integration of disabled workers. And not even in these limited areas does any binding law currently exist to protect the rights of disabled EU citizens. Several European Parliament resolutions and reports on the human rights of disabled people which have been passed during the last 10 years have improved the situation to some extent. Over the last two years, the European Commission has been examining the problem of violence against disabled people in EU countries. In addition, the Commission has announced plans for one recommendation on how the equalisation of opportunities for disabled people should be achieved and another on the implementation of the standard rules within the European Union. The best means of implementing the rules in the EU would be an anti-discrimination clause in the Community's primary legislation. At present the treaties do not mention disabled citizens, nor do any of their provisions meet the needs of disabled people. As a result of extensive representations by the disability movement to the EU bodies and related institutions, it is now widely accepted that this is a disadvantage. Discrimination on the grounds of disability is widespread and rarely are there legal or non-legal remedies to protect the victims. Under these circumstances, it is important that the treaties should contain a reference to disabled people and a clear legal statement that the principle of equality will be applied to disabled EU citizens. A firm commitment to eliminate disability-based discrimination needs to be included in primary Union legislation. A draft anti-discrimination clause has been drawn up and will be presented to the authorities in the near future.

While the adoption of the standard rules can be seen as an important step forward, we should bear in mind that there is still a long way to go. National anti-discrimination legislation, a UN ombudsperson for the human rights of disabled people, a strong international anti-discrimination convention and an anti-discrimination clause in the EU treaties are just a few of the other goals which remain to be achieved. The standard rules are not an end in themselves; they can only – and must – be used as a tool for further progress. The 1996 intergovernmental conference is an important opportunity for that to happen.

(*) *United Nations Economic and Social Council Commission on Human Rights, "Human Rights and Disability", final report prepared by Mr Leandro Despouy, 12 July 1991*

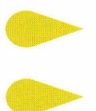
Theresia Degener
*Lecturer and researcher
Faculty of Law
University of Frankfurt
am Main
Member of the European
Task Force on Human Rights
of Disabled Peoples'
International
Am Dornloh 15
D-42389 Wuppertal*



Putting words into action:

the value of the standard rules for the European Union

Though they are not legally binding, the standard rules provide a strong political and moral commitment for all governments to achieve full participation and equal opportunities for disabled people. The panel of experts assisting the UN Special Rapporteur in monitoring implementation has identified six priority areas from among the 22 rules. How are these being addressed within the European Union?





[Rule 15]

LEGISLATION

The recognition of the rights of disabled people in the legislation of the European Union has been superficial and inadequate. With few exceptions, the rights of disabled Europeans are not the subject of binding measures or “hard” law, such as might be found in the treaty provisions, regulations or directives of the EU.

Instead, the position of citizens with a disability is addressed largely through the non-binding measures or “soft” law of the EU, including resolutions and recommendations.

So the social and economic integration of disabled individuals at the European level has been attempted through the European Social Fund, action programmes (such as HELIOS and HELIOS II) and initiatives such as HORIZON. These emphasise the facilitation and exchange of information, technical cooperation and the development of policy initiatives (all required by the UN standard rules), rather than promoting legal rights. Similarly, other non-binding instruments (such as the 1986 Council Recommendation on the employment of disabled people in the Community or the 1989 Community Charter of the Fundamental Social Rights of Workers) fail to confer legal rights or obligations in respect of disabled people. Nevertheless, such “soft” law does at least ensure that disability rights are placed upon the European agenda.

The central problem remains the uncertain legal basis in EU law for any legislation at the European level to guarantee the civil rights of disabled people. The continued failure to make progress with the proposed draft directive on mobility and transport to work for workers with

reduced mobility illustrates that uncertainty. The various provisions on health and safety, the approximation of laws within the Member States, the free movement of persons and social policy implemented further to the Maastricht treaty have all been considered (and ultimately found wanting) as the legal root from which the rights of disabled citizens might take flower. The important study by Waddington – “Disability, Employment and the European Community” (1995) – demonstrates this point, although the author argues that the 1992 protocol and agreement on social policy do provide a legal basis from which a disability rights directive might derive legitimacy.

However, some doubts remain and reformists would prefer to put the legal question beyond doubt by an early amendment to the treaty. The Commission’s 1993 consultative Green Paper on European social policy attracted many calls (most notably from the European Parliament) for positive steps to be taken by the EU to address disability discrimination. In its 1994 White Paper setting out an agenda for the development of EU social policy, the Commission recognised that the lack of legislative competence to combat disability discrimination is a serious omission. The Commission recommended a revision of the EU treaties to in-

clude a specific reference to this issue. That opportunity is likely to arise at the 1996 intergovernmental conference.

This is where the 1993 United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities may have an important role to play. The Commission had argued for the building into EU policies of a fundamental right to equal opportunities for disabled individuals, to ensure that their needs are taken into account in relevant EU legislation, programmes and initiatives, and to secure the accessibility of EU programmes so that disabled people are actively encouraged to participate therein. Most importantly of all, however, the Commission has promised to prepare an appropriate instrument endorsing the UN standard rules.

What can disabled Europeans hope or expect from this exciting rhetoric and what does it mean in terms of legislation at the level of the Union? One possibility is that the EU could adopt the UN standard rules by ratifying them like any other international agreement under international law. There are a number of problems with that approach. First, even if the EU had sufficient international legal status to enable it to accede to an international agreement, that would be unlikely to result, in any event, in the Member States being bound by the rules and thus obliged to incorporate them into national legislation. Second, the rules themselves are only a substitute or proxy for an international treaty on the rights of disabled people. Unlike a convention, the rules are not a legally binding international agreement capable of signature and ratification by sovereign States or organisations, although it is anticipated that they could become legally binding through custom and practice if sufficient nations adopt and apply them.

The rules provide plenty of scope for the EU to take legislative action in respect of the standards they set, particularly as regards the physical environment, information, communication, education, employment, income maintenance and social security.

The more likely approach is that the EU could regard the UN standard rules as a template or framework for legislative action, which the Member States would have to observe and implement nationally. That appears to be the implication of the White Paper's commitment to prepare an appropriate instrument endorsing the standard rules.

The rules provide plenty of scope for the EU to take legislative action in respect of the standards they set, particularly as regards the physical environment, information, communication, education, employment, income maintenance and social security. They "imply a strong moral and political commitment on behalf of States to take action for the equalisation of opportunities" for disabled people (paragraph 14). The use of the term "equalisation of opportunities" denotes "the process through which the various systems of society and the environment (...) are made available to all, particularly to persons with disabilities" (paragraph 24). This finds an echo in the commitment in the EU White Paper to take concrete action to combat disability discrimination.

Of particular interest as we approach the 1996 intergovernmental conference are those aspects of the standard rules which deal with implementation measures. Rule 14 requires States to ensure that disability is a consideration in all relevant policy-making and national planning. Moreover, States have a responsibility "to create the legal bases for measures to achieve the objectives of full participation and equality" for disabled people (Rule 15). Furthermore, Rule 20 provides that States should

monitor and evaluate disability programmes to ensure compatibility with the implementation of the rules.

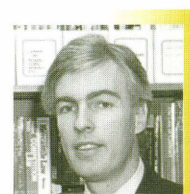
A new article inserted into the Treaty of Rome could provide the legal basis "for measures to achieve the objectives of full participation and equality" as Rule 15 requires and might avoid the problem of individual States opting out of any novel obligations. Article 119 of the existing treaty (establishing the principle that men and women should receive equal pay for equal work) perhaps provides a model for such a treaty revision. That article has been the important legal foundation for numerous binding directives implementing the principle of equal treatment in employment, training and social security regardless of gender. A suitably drafted "anti-discrimination" or "equal treatment" clause in the amended treaty would furnish disabled Europeans with directly enforceable social, economic and cultural rights. More significantly still, it would provide the legal mandate for further EU legislation, particularly in the form of directly enforceable, binding directives that would require Member States to incorporate the right to non-discrimination or equality of opportunity (including reasonable accommodation and positive action) into domestic laws and practices (as the UK government is currently doing with its Disability Discrimination Act).

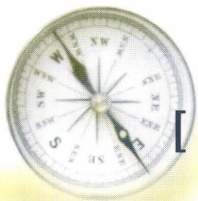
All this suggests that in 1996 disabled Europeans will have expectations that the EU treaties will be amended to provide the legal competence to legislate for disability rights. Those expectations have

been raised by the 1994 White Paper. The UN standard rules provide the agenda for the debate as to which disability rights should be recognised by the EU and in what form. However, the precondition for that debate is that the EU should take legal competence in this area and provide a firm legal basis from which future legislation can derive its authority. Much will depend upon political will, as much as the skill of the legal draughtsman.

Professor Brian Doyle

*Faculty of Law
University of Liverpool
PO Box 147
UK-Liverpool L69 3BX*





[Rule 17]

COORDINATION OF WORK

The aim of this issue of *HELIOSCOPE* is to examine the six priority areas in the context of EU action.

The rule relating to the coordination of work has not been explored fully. This rule has four recommendations and calls for independent, permanent and legal status for national coordinating committees or similar bodies to serve as a national focal point on disability matters. Such committees, it states, should be composed of private and public organisa-

tions: government ministries and disabled people's NGOs, etc. In a number of Member States, HELIOS coordinating committees have been set up. The role of these and similar committees will be reported on in *HELIOSCOPE* in 1996.

The standard rules: a milestone in the disability field

1981 UN International Year of Disabled Persons

1982 The UN General Assembly adopts the World Programme of Action concerning Disabled Persons, calling for worldwide recognition of disabled people's basic human right to participation.

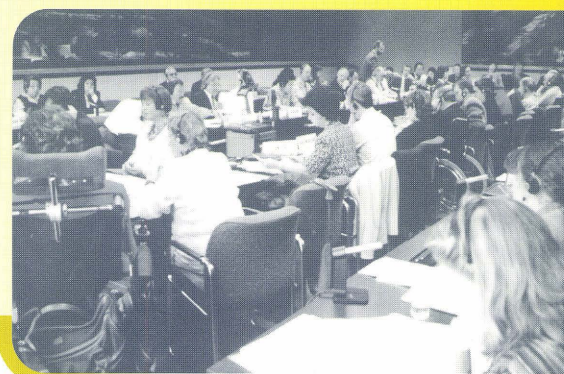
1983-1992 UN International Decade of Disabled Persons. At the end of the decade, the UN General Assembly proclaims 3 December of each year the International Day of Disabled Persons.

1993 Following consultation with more than 70 government delegations and all the major disability organisations, the General Assembly of the UN adopts the Standard Rules on the Equalisation of Opportunities for Persons with Dis-

abilities. For the first time, agreement is reached on an international instrument which can be used to encourage, influence and guide action to promote the full participation of disabled people in society on equal terms with their fellow citizens. The rules are mainly the result of the request voiced by the international disability community in the mid-1980s for stronger leadership from the UN in the implementation of the measures suggested in the world programme of action and more concrete guidelines for action at national and international level.

1994-1997 The standard rules provide for an initial monitoring period of three years (1994-1997) for the implementation of the rules throughout the

world. The panel of experts assisting the UN Special Rapporteur in the monitoring exercise, comprising 10 representatives of international disability organisations (Disabled Peoples' International, Inclusion International, Rehabilitation International, the World Blind Union, the World Federation of the Deaf and the World Federation of Psychiatric Users), has identified six priority areas amongst the 22 rules: legislation (Rule 15), coordination of work (Rule 17), disability organisations (Rule 18), accessibility (Rule 5), education (Rule 6) and employment (Rule 7).



DISABILITY ORGANISATIONS and the UN standard rules

Rule 18 of the UN standard rules reiterates the role of organisations of disabled people in representing disabled people at national, regional and local level and their advisory role in decision-making on disability matters.

An illustration of the importance of Rule 18 is the development of the European Disability Forum, the main advisory body for disabled people within the HELIOS programme (see *HELIOSCOPE* No. 1 for details). The positive lessons learned since its establishment in 1993 should contribute towards the establishment of a new consultative structure at the end of 1996 with a much broader mandate and sufficient resources to access the necessary expertise on specific issues from among the disability community for all EU programmes, actions and initiatives which impact on the lives of disabled people. The structure, modus operandi and accountability of this body has been the subject of detailed discussion by a working group set up at the September meeting of the forum – which is composed of both NGOs and Commission representatives – and a survey among its current members by the Chair, Johan Wesemann. Recommendations will be discussed at the December meeting of the forum.

On a more general level, what are each NGO's aspirations in relation to the UN standard rules? What is their role in implementing them? We asked members of the forum for their views; below is a selection of the responses we received.

The European Blind Union

The UN standard rules provide us with an excellent campaign tool to raise awareness and break down barriers to equality for blind and partially sighted

people. We are currently focusing on Rule 5 to highlight the importance of accessible informal information and communication to promote independence for visually impaired people.

European Regional Council of the World Federation of Mental Health

As long as people with mental health problems are discriminated against, stigmatised, compulsorily detained and treated without adequate safeguards, abused and denied their human and civil rights, the UN standard rules will be purely a set of ideals. Our organisations must strive to make them a reality.

Autism Europe

The UN standard rules represent a powerful tool for us – and are completely in tune with our charter. However, as they are not compulsory, the UN standard rules must be advocated by all disability organisations. It is up to us, disabled people, as full citizens and consumers, to ensure our governments adhere to these basic human rights provisions.

Rehabilitation International

The UN standard rules are a major reference tool for the development of a global policy on the full participation of disabled people. Their importance and impact will be determined by their implementation by the Community as a whole. At all levels and in all areas, they must become the respected norm.

COFACE

The UN standard rules are fundamental for the equalisation of opportunities for disabled people. Numerous references to the family reaffirm our conviction of the family's role in relation to disability. When families unite in solidarity for common action, genuine equality is achieved through awareness and the acceptance of differences.

Disabled Peoples' International

DPI is a human rights organisation. The UN standard rules are the principal, most important document we can use to do our work – we can use its universal acceptance to implement disabled people's rights throughout the world. We firmly believe the standard rules provide the building blocks from which we can make a society for all.

International League of Societies for Persons with Mental Handicap (ILSMH-EA)

The ILSMH-EA welcomes the standard rules as an important monitoring mechanism and a powerful tool. It is the first time that minimum standards in this area have been agreed internationally. Our main task is to promote them: we would like to see them turned into a UN convention to make them stronger.





ACCESSIBILITY

In the rules, accessibility refers to two fields of action: "States should (a) introduce programmes of action to make the physical environment accessible; and (b) undertake measures to provide access to information and communication."

The first of these, access to the physical environment, has four components:

1. development of standards, guidelines and, where appropriate, legislation for access to housing, buildings, transport, streets and other outdoor environments;
2. information for architects, engineers and other design professionals on access policy and suitable measures to ensure access;
3. incorporation of accessibility requirements in design and construction from the beginning of the design process;
4. consultation with disability organisations when developing norms and standards, and local involvement of these organisations in public construction projects.

The second, access to information and communication, has seven components:

1. provision of accessible information for disabled people (and their families) on diagnosis, rights, services and programmes;
2. development of programmes using appropriate technologies to make information and documentation available to people with visual impairments, auditory impairments and communication difficulties;
3. use of sign language in the education of deaf children and use of sign language interpreting services generally;
4. consideration for the needs of people with other communication disabilities;

5. accessible media, especially television, radio and newspapers;
6. accessible computerised information and service systems;
7. consultation with disability organisations when making information services accessible.

The accessibility challenge

From a policy-making point of view, Rule 5 presents an interesting challenge, since it targets both desirable results and desirable processes for achieving those results. Even with the best political will, the implementation of accessibility measures requires cooperation between many levels of government and administration from the State and the civil service to grassroots organisations.

Appropriate political and organisational structures which involve disabled people are often lacking, especially in the developing countries. Suitable human, financial and physical resources may also be scarce.

Nevertheless, in 1993 the United Nations could report that "...one of the areas in which the greatest results have been achieved in the past decade" is in the removal of physical and architectural barriers (1). Particular progress had been made in many States towards making public buildings accessible for disabled people, for instance by levelling pavements, marking parking areas, fitting automatic doors, widening lifts and installing toilet facilities for wheelchair users.

Some countries had given priority to improving housing, others had also adopted measures to facilitate access to shops, museums, art galleries and commercial and entertainment centres.

These efforts, besides being practical achievements in themselves, remind us that physical barriers to accessibility have tremendous symbolic importance both for disabled people and for citizens in general. To the surprise of many people, designs which take the needs of disabled people into account prove to be functionally more suitable for "broader average" members of the population at large as well, e.g. small children, people carrying luggage or with shopping trollies, pregnant women and frail, older people. "Design for all" or "universal design" is functional design for the "broader average" person, which carries with it the message of fundamental equality between those who are disabled and those who are not. Integrated solutions should be found to cater for particular disabilities which are not encompassed in "broader average" designs. This approach to architectural, industrial and environmental design is supported by the work of the new European Institute of Design and Disability, which promotes activities along these lines. How much better our surroundings would be if they were designed with the needs of disabled people in mind from the start, thus avoiding complicated and expensive alterations to improve access at a later point in time!

In the area of accessible transport worldwide, there would appear to be very many examples of good practice, e.g. low-cost public transport schemes, special and adapted vehicles, personal travel allowances, seating and safety systems, navigational systems for visually impaired people based on information technology, and so on. What is lacking, however, is an integrated, coherent approach to accessible

“Design for all” or “universal design” is functional design for the “broader average” person, which carries with it the message of fundamental equality between those who are disabled and those who are not.



transport. As a result, accessible solutions are unevenly distributed, which creates major problems for the participation of disabled people in society, especially those living in rural districts.

The development of information access and communication systems for disabled people presents the same principal difficulties as the design of the physical environment, with the added disadvantage that here the problems are – at first glance – less “noticeable” and therefore less likely to attract the attention of designers. Mainstream computer software, computer interfaces and most telephones, for example, are not designed to cater for those whose abilities – physical or mental – lie outside the average range. In this field, specialist research and development organisations are now concentrating on making existing information systems accessible for people with visual or hearing impairments or who have difficulties learning or understanding.

Towards implementation of the UN accessibility rules

The UN targets for accessibility are well in keeping with the consensus which is developing in the HELIOS programme, and particularly in its working groups on accessibility, transport and technical aids. Indeed, it could be said that the HELIOS programme as a whole provides an unparalleled example of international cooperation, which can further the implementation of the UN rules through the involvement of a very broad range of interest groups. Working from this common background, HELIOS and all its members and partners should be able to serve as a catalyst for the implementation of the UN rules. What is, however, essential, is that the rules are put into effect in a systemic way, and not simply in a piecemeal fashion, one by one.

Another example from the accessibility field illustrates why a systemic approach is necessary. In several EU countries there are differences between the standards specified in building regulations and directives and standards for building adaptations eligible for public support through loans, subsidies and contributions. And both may be different again from the standards contained in guideline design recommendations. This situation can easily give rise to confusion about what “accessible design” really means and create administrative pitfalls for disabled people, well-meaning architects and housing providers alike.

A systemic approach to implementation of the UN rules might be based on the following outline for policy formation – taking “accessibility” as an example – where appropriate:

- implementation and evaluation of the results of the target measures should be systemic (and not case-by-case);
- traditional planning systems and traditional design solutions should be reconsidered in the light of alternatives and experimentation on a broad scale;
- research agendas for physical accessibility and access to information and communication should incorporate end users’ interests and priorities;
- end users should take an active part in design research and development work on user-related aspects of physical accessibility and access to information and communication;
- there should be specific analysis of and action on existing problems (e.g. inaccessible structures), taking into account the cultural, technical, social and economic aspects of each case;
- subsidies and incentives should be found to encourage accessible solutions in general;
- conflicts of interest concerning accessibility should be given full considera-

tion, with independent guidance or arbitration where necessary;

- information exchange should be encouraged within a broad, cooperative and democratic framework.

The UN rules will require strong international cooperation if they are to be implemented widely. In the EU, some of the structures and mechanisms which may further such implementation are already in place and many positive examples of practice and cooperation can be drawn upon to support the work ahead. Locally, nationally and at European level, active participation is required on the part of all interest groups, including users, experts, practitioners and politicians. The implementation of the UN rules provides an undeniable opportunity to make the next step forward towards accessibility for all disabled people in Europe.

(1) United Nations (1993), “Human Rights and Disabled Persons”, *Human Rights Study Series*, No. 6, Geneva

Ivor Ambrose
Senior researcher
at the Danish Building
Research Institute
Dr. Neergaards Vej 15
DK-2970 Horsholm





[Rule 6]

EDUCATION

The United Nations standard rules are naturally a fresh source of inspiration in the field of education for disabled people. The principles are easy to subscribe to; their application, however, poses rather more problems. The challenge for education is no doubt greater than might at first appear.

The standard rules should not be viewed in isolation. Strong and ever increasing support for their position is apparent in the principles and recommendations issued by other international organisations, in particular by UNESCO (Salamanca, 1994) and the OECD (Maastricht, 1994 and Washington, 1995) and at various seminars held in the framework of the European Union's HELIOS programme.

Although the document's recommendations on education are in the main contained in Rule 6, we should also take due account of the fundamental concepts laid down in the introduction. In particular, its definitions of the terms "disability" and "equalisation of opportunities" are central to the subsequent guidelines on education.

In specialist circles, it has become standard practice to eschew the automatic connection which used to be made between the terms "disability" and "impairment". This is an acknowledgement of the fact that society and education are also influential in determining disability. We speak of "disabled pupils", defining their disability with reference not only to an impairment but also to specific educational factors – at all levels, from policy development to the classroom.

A glance at the legislation, however, reveals that only a few Member States define the concept of disability in the same way as the standard rules. The concept of "special needs", long established in the United Kingdom, meets with only grudging acceptance in other countries, at least in the full meaning of the term. In some

countries, indeed, recent decisions have adhered to the traditional definitions, which identify the individual with his or her disability. This is to disregard the relative nature of disablement. In those countries, the message has by and large not reached the grassroots – namely the teacher in the classroom – that the school itself is the principal source of, sometimes the cause of, and always a contributing factor in disability or learning difficulties. And the result is often exclusion.

The dynamic definition of "equalisation of opportunities" also presents a new challenge. The rules state that general educational authorities are in principle responsible for the education of every disabled pupil. Physical access to the buildings is usually possible, but that is just one factor. The idea that the education system should adapt to the individual capacities and needs of students is quite new for most countries. The principle may be upheld in the legislation of certain Member States, but there are only isolated examples of adapted curricula and flexible organisation.

Rule 6 deals specifically with education. Its nine points make a number of major recommendations. We will limit our discussion here to the key ideas.

1. All education for disabled people should be an integral part of the educational system. This is already the case in most countries; for others it is a hurdle that remains to be cleared. But integrating as many pupils as pos-

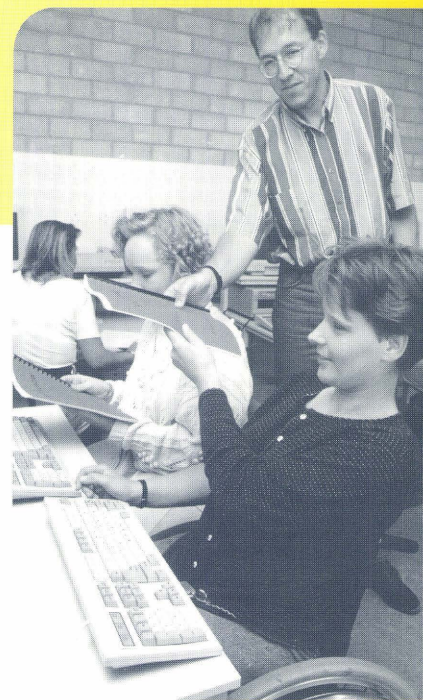
sible into mainstream education is a very costly undertaking for most EU Member States. Its practical implementation remains a long and difficult process for all countries, and one in which they must follow the lead of a few pioneers in the field.

The principal challenge of integrated education is that the solution should not really come from outside the school, from specialists brought into the education system. Systemic change must come from within the system to develop "a school for all", bringing "inclusive education" to every classroom.

What is required is similar to the provisions of programmes for other minority groups (migrants, the underprivileged, etc.), which state that schools must make allowances for diversity in society. The parallel is not universally accepted, however. In many countries, special education has acquired a very positive status. It is too often seen as a convenient alternative. This progressively diminishes the responsibility of the mainstream school and leads back to the vicious circle of powerlessness and exclusion or segregation.

2. Nobody would dispute the fact that support and assistance are needed to bring about the necessary changes. But here too a major shift of emphasis is apparent. Traditionally, specialists on a given impairment or area of

The principal challenge of integrated education is that the solution should not really come from outside the school, from specialists brought into the education system. Systemic change must come from within the system to develop “a school for all”, bringing “inclusive education” to every classroom.



study provided special assistance to correct or coach the pupil so that he or she could adapt and keep pace. Implementation of the standard rules requires, first and foremost, helpers to support mainstream schools and assist them in progressively extending their care provision and achieving the necessary conditions for integration within each class – without, however, undermining the central role of the teachers themselves.

This is a new approach to educational support and assistance, complementary to and operating primarily within the school itself. The role of the teachers and the school as a whole is central; all other action must be tailored accordingly.

This approach, which is indeed a real break with the past, is gradually gaining ground in most EU Member States. But in far too many countries the specialist and continuing training for teachers and assistants which is needed to make this a day-to-day reality is not yet out of the starting blocks. Yet this remains essential for progress.

3. Policy-makers are asked to comply with these guidelines. Above all else, this means that they must make their policy clearly understandable to all concerned. Some European countries which have played a pioneering role in the field of integration have achieved this to admirable effect. Their legislation has been adapted,

the process has been conducted openly and at all levels of society, and policy formulations have become simpler as a result. Examples of this are the recent education act in Spain and cases in Denmark and Italy.

Policy also has a crucial role to play in coordinating all those measures, both inside and outside the education system, which contribute to this process. Educational measures must be aligned with programmes in other areas of society. This is probably the biggest challenge facing us over the next few years. In too many countries, disabled people are still compartmentalised in separate departments and services. Debate and harmonisation is sporadic. Nevertheless, there have been some laudable attempts to correct the situation.

Countries which already have a highly developed system of special education are called upon to recognise the provisional nature of such arrangements and to undertake a systematic integration of mainstream and special education. Where possible, organised forms of cooperation should be the first step.

It is thus clear that for most European Union countries the United Nations standard rules are a challenge to introduce and progressively implement genuine systemic reforms. The planning and implementation must be undertaken together with all those previously involved

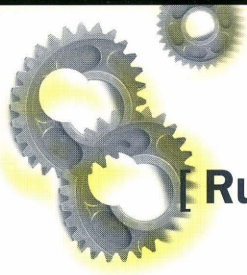
in special education, including, first and foremost, disabled pupils and their parents, and also helpers. The focus in mainstream education must be the classroom itself. We would therefore like to end by quoting Dr Dianne Ferguson (University of Oregon, USA), expert and mother of a seriously disabled daughter: “Systemic reform will only be systemic enough when the agendas of special, integrated and regular education are meshed in order to achieve a unified system of public education that incorporates all children and youth as active, fully participating members of the school community; that views diversity as the norm; and that maintains a high quality education for each student by assuring a meaningful curriculum, effective teaching and necessary supports.”

** The author would like to thank Dr Seamus HEGARTY (UK) and Mr Jørgen HANSEN (DK) for their constant inspiration and cooperation, without which this article could not have been written.*

***August Dens**

*Director
Centrum voor Begeleiding van
Speciaal en Geïntegreerd Onderwijs
Constantin Meunierstraat 49
B-3000 Leuven*





[Rule 7]

EMPLOYMENT

One of the most admirable features of the UN standard rules is that they set out a clear policy goal for the employment of disabled people: “The aim should always be for persons with disabilities to obtain employment in the open labour market,” though sheltered or supported employment may be an alternative for people “whose needs cannot be met in open employment”.

This is a goal which is likely to win widespread support. In the HELIOS programme, the European Union has already adopted the goal of promoting the integration of disabled people into wider society, in all spheres, including employment.

At the same time, when fully understood, this goal does set the Member States of the Union a genuine challenge. Disabled people often face a labour market which is discriminatory, exclusive and inaccessible.

How do the standard rules indicate that we should work towards this goal?

“States should recognise the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment. In both rural and urban areas they must have equal opportunities for productive and gainful employment in the labour market.”

In its opening passage, the standard rule on employment sets out the UN’s two-handed strategy for the employment of disabled people: on the one hand, disabled people must have equal opportunities – with the implied necessity of removing negative factors. On the other hand, positive support should be offered – disabled people must be empowered.

The first element is elaborated on in the first paragraph of the rule: employment laws and regulations must not discriminate

against disabled people. Perhaps a greater challenge to policy-makers is to be found in the second half of this paragraph: employment laws and regulations “must not raise obstacles to their employment.”

The next two paragraphs of the rule are devoted to providing positive support for disabled people’s employment. They amount to an extensive programme, in three realms:

- workplaces and premises should be accessible to disabled people;
- adaptations and special equipment which enable disabled people to do various jobs should be made available;
- training and other support (such as interpreter services) should be available to individual disabled people.

The measures by which this positive support should be provided are also indicated: vocational training, employment quotas, designated employment schemes, technical and financial assistance for the employers of disabled people and contract compliance.

This is not a comprehensive programme: it does not address the need for enforceable legislation to counter discrimination against disabled people. Nor does it address the vital policy issue of ensuring coherence and synergy between employment and other areas of public policy: disabled Europeans will never have equal opportunities in employment as long as education, transport and housing are inaccessible to them.

It is, however, an extensive programme. What is particularly impressive is that several paragraphs are devoted to changing attitudes towards disabled people. To change these attitudes, the rule on employment proposes a parallel programme of action, with the State having responsibility for public awareness campaigns, while the social partners cooperate to ensure that there are equitable policies within enterprises.

How might the rules be implemented in Europe?

The Commission’s White Paper on European Social Policy proposes an “appropriate instrument” endorsing the standard rules.

European legislation embodying the standard rule on employment would certainly be practicable. The policy goal of integrated employment, buttressed by supported or sheltered employment, is unlikely to be controversial.

The range of policy measures to achieve this goal – quotas, public awareness campaigns, support for employers of disabled people, joint action by the social partners – is very similar to that proposed in the Council’s 1986 Recommendation on the employment of disabled people in the Community (OJ L 225, 12.8.1986, pp. 43-44).

Furthermore, some of these measures have already been adopted by all the Member States. The extent of implementa-



European legislation embodying the standard rule on employment would certainly be practicable. The policy goal of integrated employment, buttressed by supported or sheltered employment, is unlikely to be controversial.

tion varies from one Member State to another, and none has adopted all of them.

How effective has the 1986 recommendation been?

On the one hand, in France, the recommendation was followed by the law of 1987 on an employment quota for disabled people, which is generally recognised as being very effective. On the other hand, the UK has just passed legislation which is, in some respects, in advance of provision in other Member States but which, at the same time, abolished a much less effective quota.

While Member States might have difficulty accepting all the measures proposed in the UN standard rule on employment, it would be difficult to claim that this programme of measures would represent a radical departure in European policy-making.

It must be recognised, however, that existing policies, at national and European level, including the 1986 recommendation, have not achieved complete success.

In 1989, the Council issued its conclusions on the employment of disabled people in the Community (OJ C 173,

8.7.1989, pp. 1-2), which recognised "that, in spite of the efforts by Member States, disabled people are continuing to experience difficulty in gaining access on an equal basis to vocational training and employment and that their unemployment rate is appreciably higher than that of the population as whole." Although the Council considered that improvements in the employment situation for disabled people must be achieved essentially through general economic measures, they recognised that, to guarantee equal opportunities, additional special measures were required.

The European Commission included in its Medium Term Social Action Programme, which was published earlier this year, a commitment to focus in 1996 on the issue of the employment of disabled people in the overall context of its follow-up to the European Council meeting in Essen, and to issue its proposals in the first half of 1997. This is a further acknowledgement of the continuing need for improvements to be made.

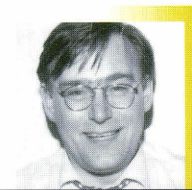
I want to conclude this article on a controversial note.

To build on the possible consensus for the standard rule on employment whilst overcoming the failures of policies so far, a more forceful instrument than a recommendation is needed. On the other hand, the use of such an instrument could destroy that consensus.

This may be an opportunity for a framework directive, which would provide for the flexibility needed in adapting the standard rule on employment to national situations. Whilst this flexibility would meet many of the legitimate concerns of Member States, it would also place upon them obligations requiring more attention and closer adherence than a recommendation.

Richard Exell

*Disability policy officer
Trades Union Congress- London
Congress House
Great Russell Street
UK-London WC1B 3LS*



The standard rules as a policy

At European

The principles adopted by the United Nations have always been one of the key points of reference for Community action to assist disabled people. Readers will remember that it was in the framework of the International Year of Disabled Persons that a resolution of the Council and of the representatives of the governments of the Member States was adopted, on 21 December 1981, on the social integration of disabled people.

Subsequently, in the framework of the International Decade of Disabled Persons, the Community adopted various measures including:

- the Council Recommendation of 24 July 1986 on the employment of disabled people in the Community, which urges the Member States to "take all appropriate measures to promote fair opportunities for disabled people in the field of employment and vocational training" and to pursue their policies, particularly those providing for the elimination of the discrimination faced by disabled workers; the recommendation also sets out a guideline framework for positive action;
- the HELIOS (1988-1992) and HELIOS II (1993-1996) programmes, designed to promote social integration and indepen-

- dent living for disabled people by various general and specific means;
- the Resolution of the Council and the Ministers of Education meeting within the Council of 31 May 1990 concerning the integration of children and young people with disabilities into ordinary systems of education.

These measures were the Community's – at times substantial – contribution to the development of Member States' own initiatives to implement the World Programme of Action concerning Disabled Persons.

The Commission's proposal, under its new social action programme, to submit a recommendation on the application of the UN standard rules thus represents first and foremost the continuation and strengthening of a policy that goes back over a decade.

This is not to ignore the fact that disability policies have their own history, legislative framework (constitution, civil law and social provisions), mechanisms and structures in each country. Responses to the challenge of equal opportunities will vary from one national context to another, and the measures required fall largely to the Member States and/or, increasingly, policy-makers at local and regional level.

instrument

level

Accordingly, in line with the principle of subsidiarity, the Commission plans to put forward a legal text combining:

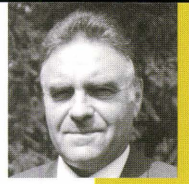
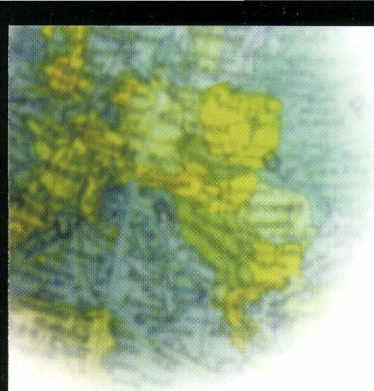
- a strong and solemn political commitment on the part of the Union and the Member States to promote equal opportunities for disabled people;
- a reference framework for the national measures required to promote equal opportunities for disabled people and an encouragement for Member States to introduce new initiatives;
- a framework for policy assessment and information exchange between the Member States;
- a guide for the development and assessment of an appropriate policy within the Community's sphere of action;
- an instrument for international cooperation, particularly with eastern Europe.

Nor should the important equal opportunities policy issue of implementing anti-discrimination legislation be forgotten.

B. Wehrens

*Head of the Division
"Integration of disabled people"*





Willy Taminiaux
*Minister for Social
Action, Housing and Health
of the Region of Wallonia*

At national level

First and foremost, the standard rules concern the Member States. How should they respond? In Belgium, disability policy is for the most part the responsibility of the regional authorities. The Region of Wallonia recently conducted a thoroughgoing review of its policy – probably one of the first instances of the standard rules being applied in Europe. We talked to Willy Taminiaux, Minister for Social Action, Housing and Health.

The rules uphold disabled people's right to equal opportunities and participation in social life – two principles enshrined in a new decree issued by the Region of Wallonia on a comprehensive integration policy.

Our policy reform proposals are based on three key principles laid down in the rules. Firstly, the principle that priority should be given to opening up access for disabled people to universal services, i.e. standard structures such as social and medical services, schools, businesses, housing, transport, etc. Secondly, that efforts should be made to ensure that disabled people can remain in their ordinary environment wherever possible. And, most importantly, that disabled people should be involved in every decision that concerns them.

A key demand of disabled people...

... and one which calls for recognition and encouragement for the development of associations of disabled people to defend their interests. That is why we have set up an independent body, the Conseil consultatif wallon (Walloon advisory council), which is composed essentially of disabled people and their representatives. The council delivers opinions on our policy proposals, and is thus involved in establishing and organising the services it

feels are required. Furthermore, the Agence wallonne pour l'intégration des personnes handicapées (Walloon agency for the integration of disabled people), which will be responsible for implementing the new policy, will be involving associations representing disabled people in the work of its various administrative and advisory bodies.

One of the points stressed in the decree is the need to improve coordination between existing services to increase their effectiveness – as the standard rules recommend.

That is the agency's main function: reorganising available resources and encouraging local and multisectoral planning of existing services. That means both specific services such as medical, social and educational institutions and sheltered workshops, and general facilities which do not cater only for disabled people: social assistance offices, home care centres, family support services, mental health and functional rehabilitation centres, etc. In the past, fragmentation or, conversely, excessive centralisation may have undermined their efficiency. But, naturally, our primary objective is to open up access to ordinary structures: schools, businesses, housing, streets, etc.

It is an ambitious project for a country where disability policy up to now has been to establish a parallel system of specific structures.

The decree is intended as a reference framework for social changes which are not going to happen overnight, but which are nonetheless essential. An integrated policy of the kind we envisage cannot be confined to rehabilitation, financial assistance or specific protection for the individual. Disabled people must be integrated whenever possible into the region's mainstream structures: as regards the economy, the labour market, housing, town planning, transport and so on. That is our aim in ensuring the active involvement of the entire cabinet of the Region of Wallonia and all the local authorities answerable to it in implementing this initiative. Integration is a matter not for individual officials but for all of us in our respective spheres of competence. I believe in partnership – and in putting effective measures into practice in the field.

At grassroots level

The rules as a tool for campaign work

“The rules are no good unless governments follow them.
All member States of the United Nations have agreed to them.”

Your decree fundamentally redefines disability policy. The fact that it was modelled on an instrument adopted by the United Nations must have helped in getting it passed.

That is undoubtedly true – despite the fact that the standard rules are not legally binding. Their strength lies in the grassroots movement that prompted them: the mass demand of disabled people, in essence, for independence and an end to segregation.

Yet that demand is not always taken into consideration in the development of national policies in Europe. What is your view on the possibility of a political initiative at Community level to promote the application of the standard rules in the Member States?

I think that is not only essential – it is also the democratic option. Since the UN rules were formulated in response to a popular movement, it is entirely logical that European Union initiatives should take them on board. Moreover, although most of the responsibility in this field falls to the Member States and their regional authorities, the Union has a contribution to make in promoting convergence between the efforts of the various parties.

This quotation comes from an information kit prepared by Disability Awareness in Action (DAA) on the standard rules. The kit is designed to assist disabled people and their organisations in ensuring that their governments abide by the rules.

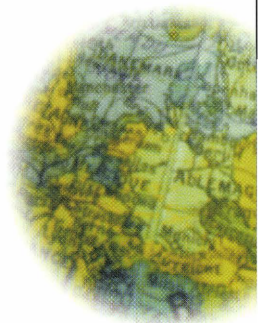
It explains very clearly what disabled activists can do to encourage governments, local authorities and communities to look at the barriers to disabled people's participation in society, and to advise them on the best way to get rid of these barriers and meet the standards set in the rules.

As well as providing a brief overview of the rules, the kit gives guidance centred on the following 10 action points for organisations representing disabled people:

1. Learn about the rules
2. Find the government department which is the focal point within the government for the rules
3. Talk to officials
4. Share information
5. Collect information
6. Coordinate work with other organisations
7. Use the media
8. Inform the Special Rapporteur of what is happening in your country
9. Know what you are talking about
10. Work at all levels

The kit is available from Disability Awareness in Action (DAA), 11 Belgrave Road, UK-London SW1V 1RB in English, French and Spanish, in large print, on audio cassette and on ASCII 3.5" disk.

DAA is a worldwide public awareness campaign supporting the work of disability organisations at local, regional, national and international level. DAA provides campaign and development resources in print and alternative media and a network for the exchange of ideas and experiences. Organisations involved: Disabled Peoples' International, Inclusion International, IMPACT, Rehabilitation International and the World Federation of the Deaf.



News

from the Disability Intergroup

MEPs on the Disability Intergroup recently had the opportunity to hear Bengt Lindqvist's stimulating presentation on the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. Disabled people worked at international level to get these rules adopted; now it is the responsibility of European legislators, such as MEPs, and national legislators to use them to the maximum extent possible to ensure full civil rights for disabled people.

Bengt Lindqvist's presentation showed MEPs that the rules are the most progressive international instrument for promoting the human rights of disabled people. We are now committed to ensuring that, in our work in the European Parliament and outside, the rules are used to "disability-proof" policy, programmes and products to ensure that they are accessible. This is also in line with Commission policy outlined in the White Paper on social policy.

So, with the UN standard rules in mind, MEPs active on disability issues have put forward a number of amendments to the European Union's budget. These include amendments to areas as

diverse as promoting the access of disabled people to EU programmes in the areas of art, overseas development and minority languages (sign languages) as well as the more obvious areas such as ensuring information policy is accessible to disabled people. An amendment to the HELIOS budget has also been proposed to ensure specific work on implementing the rules at EU level.

One of the major priorities agreed by disabled people at European level is the revision of the Maastricht treaty to ensure that a clause on non-discrimination on the grounds of disability is included.

The rules can also be used by MEPs in work outside the European Parliament. For instance, Rule 6 states that measures must be taken to ensure that new computerised systems are accessible to disabled people. Following representations from Mary Banotti MEP and visually impaired people, Microsoft appears to be bending to pressure to have a version of Windows 95 available soon for people with visual disabilities.

One of the major priorities agreed by disabled people at European level is the revision of the Maastricht treaty to ensure that a clause on non-discrimination on the grounds of disability is included. Implementation of this at the intergovernmental conference would be in line with Rule 15, which says that States have a responsibility to create the legal bases for measures to achieve the full participation of disabled people. All the Member States have signed the rules and so in theory should have no problem with creating an appropriate legal base at European level. The rules are there; now it is up to us to use them.

Barbara Schmidbauer
MEP, Chair and
Mary Banotti
MEP, Vice Chair
Disability Intergroup



Quarterly publication of HELIOS, the Community action programme to assist disabled people. Available free of charge in the 11 official EU languages. HELIOSCOPE is published on behalf of the European Commission, DG V/E.3, Integration of disabled people division, but does not necessarily reflect its official views. The logos, illustrations and photographs may not be reproduced.

Editor responsible: Philippe Lamoral, Director of the HELIOS Team of Experts. **Editor:** Claudia Ritter, **reader service:** Mary van Driel, **editorial coordination - NGO unit:** Nicola Bedlington. **HELIOS Team of Experts**, avenue de Cortenberg 79, B-1040 Bruxelles, Belgium. Tel.: +32.2 738 06 22/23. Fax: +32.2 735 16 71. **Photographs:** Marie Mandy. **Translation and graphic design:** CONTEXT LANGUAGE SERVICES and Signé Lazer. *Printed on non-chlorine-bleached paper.*