

HELIOSCOPE



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Feature:

functional rehabilitation

Central and eastern Europe:
strategies for cooperation

The UN standard rules

Platform of European Social NGOs



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Functional rehabilitation – a European perspective

Functional rehabilitation services are provided in all European countries. The general feeling, however, is that the situation is far from perfect. And improving it is not simply a question of financial resources, know-how and technology. What is needed, in my opinion, if we are to improve the quality of life of disabled people, is ongoing debate to identify the essence of the rehabilitation process. The answers to current questions will vary according to the time and place, of course. But, nevertheless, certain basic concepts will be commonly shared – in Europe, if not throughout the world.

My own experience with patients with brain injury has brought home to me the complexity of the concept of functional rehabilitation. There are people with brain injury in every society, yet their needs continue to be misunderstood. Rehabilitation is not universally recognised as a natural response to brain injury because of earlier pessimistic assumptions that firstly, little could be done to recover brain functions and, secondly, should spontaneous recovery occur, it would be only partial and would level off within the first year or two after injury, particularly in cases of severe damage. Even when treatment is available, it may not be as comprehensive as it could be, partly owing to a lack of awareness of the benefits of neuropsychological rehabilitation, which treats the cognitive, emotional and social consequences of the injury. Economic constraints should not be a deterrent, since research has shown that effective treatment can lead to reductions in long-term State expenditure on health and social services.

Ignoring the complexity of these problems, however, does not mean they will simply disappear, nor will it lessen the suffering of those concerned. For those of us who are personally involved in the complexity of brain injury – as the person concerned, a family member, a friend, a colleague or a member of one of the caring professions –, the urgent need for intervention is readily apparent. Research findings clearly demonstrate that brain injury has an adverse impact on the quality of life of

both the individuals concerned and those close to them – not just immediately after injury but years later. Recent findings also suggest that patients can recover their functions up to 10 years post-injury, yet the value of rehabilitation and the form it should take is still questioned. I believe similar problems exist with regard to other disabilities.

For rehabilitation to have functional significance, therefore, it needs first and foremost to be tailored to the individual and to make practical sense to all concerned. The purpose is ultimately to improve the functional capabilities of patients so that they can return to a satisfying life encompassing love, work and leisure. It would be worth considering a more comprehensive approach to evaluation and treatment in a European perspective – a holistic and individualised approach that would allow functional rehabilitation to become a more widespread reality.

A holistic, individual approach means viewing disability as affecting the functioning of the person as a whole – physical, cognitive, emotional and interpersonal aspects included – and regarding the impact of such changes as unique to the individual.

If evaluation and treatment are to be on an individual basis, a creative, dynamic interplay of hypothesis testing and feedback has to be established. To do this, therapists must achieve a sound knowledge of the background of the individual in his or her present environment. Individualised evaluation and treatment, however, can take place only within a collaborative relationship based on trust. Such relationships should be nurtured and developed between the disabled person and all those involved, professionals and others. Some disciplines may be more active than others at certain stages of the process. But it is combined expertise that is likely to provide the most comprehensive treatment.

Letter from the Editor

Like a coin, integration has two indissociable sides, forming a single whole. On the one hand, there are society's efforts to adjust to the specific situation of each disabled person, and on the other disabled people's own efforts to integrate. Previous issues of *HELIOSCOPE* have looked at how employment and education can be adapted and how society can contribute to promoting social integration and "independent living". In choosing rehabilitation as this issue's theme, our aim is to cast light on the other side of the coin – how disabled people can achieve rehabilitation in order to secure maximum integration into society.

A significant factor not dealt with in this issue is the responsibility of disabled people in the rehabilitation process. Quality of life has become something of a catch phrase nowadays. In previous HELIOS II activities, disabled people identified the possibility of choosing and taking decisions in major areas, and in particular rehabilitation, as a significant factor for their quality of life. Disabled people's right to a say in the rehabilitation process is on the list of priority themes for exchange activities in 1995 and 1996.

In due course, *HELIOSCOPE* will ask the HELIOS partners working on this theme for an additional contribution to complement this issue of the magazine.

P. Lamoral

Director

HELIOS Team of Experts

The holistic and individualised approach proposed here may appear very demanding at first glance, but experience has shown it to be effective. The HELIOS exchange and information activities, with their aim of identifying the key factors in examples of good practice throughout the European Union, are helping to make this a reality – not only for people with brain injury, but for all those the approach can benefit.

Feature: functional rehabilitation

- ▶ **The geographical spread of rehabilitation services** 4
- ▶ **Ethical issues in functional rehabilitation** 6
- ▶ **Mental health and people with learning difficulties** 8
- ▶ **Vocational training for low vision therapists** 10
- ▶ **Debate: deafness, hearing impairments and rehabilitation** 11

HELIOS activities

- Guides of good practice** 13

Profile

- NGOs in the mental health sector 14

Legislation

- Germany: Care insurance – reform or nightmare? 17

Central and eastern Europe

- The HESTIA study 19
- Strategies for increasing cooperation 20

Human rights

- The UN standard rules 21

Forum

- Platform of European Social NGOs 22

Council of Europe

- The international classification of impairments, disabilities and handicaps 23

European Parliament

- Disability Intergroup 24

In the next issue

The UN standard rules – a policy instrument for the European Union?

functional rehabilitation

The geographical spread of rehabilitation services

implications for clients,
services and general health policy



Providing rehabilitation services across a whole country to meet the needs of all people with all kinds of disability is a major challenge.

All EU Member States offer a range of rehabilitation services designed to bridge the gap between acute care after an injury or illness and reintegration into society. These services have developed in different ways in different countries. These differences reflect both the size of the country and the historical development of services.

Community-based provision often backs up such services, but it tends to be general rather than specialised. So people with complex disabilities, such as arise from brain injury, may find themselves without ready access to appropriate provision. These problems are particularly intense in areas where the population is thinly scattered over a wide area and where the development of services has been geographically concentrated for historical or financial reasons. Where this occurs it can have the effect of slowing down or preventing return to maximum independence.

Furthermore, the boundaries between services often make co-ordination between their efforts to address the aspects of health, employment, interpersonal relations and leisure very difficult. As a recent government report in Scotland remarked "Rehabilitation is more about getting back into work, sex and golf (not necessarily in that order) than it is about leaving hospital". In some countries there are bodies which have responsibility for coordinating services, for example the National Rehabilitation Board in Ireland. However, in some regions, particularly the more peripheral ones, there are actually not many services to be coordinated and they are less likely to cover specialised issues. For the client this means a lack of services, while for government and service providers the potential problems and the costs involved in dealing with them are substantial.

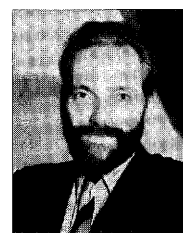
Ways must be found of delivering specialised services to enable people to remain in their own homes and communities with a maximum of independence. This means investing money and time in developing services. Development issues which need to be addressed include the need for:

- More research focused on identifying the range and scale of such needs
- Training for staff in assessing and meeting the full range of needs – multi-skilling of rehabilitation and case management specialists

- A spread of specialised services able to operate on an out-reach basis and to train people locally
- Multi-purpose community-based resources offering a range of direct services and transitional activities, including functional rehabilitation and vocational rehabilitation and training
- Support for integration and independent living: specialists able to work with and support people in school, in training and in jobs, such as job coaches
- The development of client-led self help groups at local level
- Coordination between services, perhaps through multi-agency multi-disciplinary teams, and formal coordinating bodies, including for the adaptation of the home environment

For policy-makers the implications are far-reaching. Scattered services are expensive to run. The agendas of central government ministries and of regional and local government do not necessarily coincide. There is a case for rehabilitation, in all its aspects, to have a clear focus through specific government structures at all levels, with the power to ensure cooperation. This could be based on an understanding of shared responsibility and shared cost, with the aim of providing services to enable people with disabilities to achieve maximum independence.

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Ethical issues in functional rehabilitation

Functional rehabilitation is a relatively recent discipline and largely the fruit of rapid developments in medical science after the second world war.

Until a few years ago, the ethical and deontological issues involved in functional rehabilitation were given scant consideration. It seemed more important to define the limits and scope of rehabilitation, a discipline which still has difficulty asserting its autonomous identity in the field of research and academic study and is often greeted with a certain scepticism, if not hostility. Moreover, there is widespread support for the view that the ethical and deontological issues related to developments in other areas of medicine, particularly as a result of technological advance – such as intensive care and genetic engineering –, are far more important and pressing. The attention focused – and not only by experts in these fields – on the dramatic and complex ethical issues posed by

such developments in what are considered the “pioneering” branches of medicine has diverted interest from the apparently less complex area of rehabilitation.

However, this has not stifled the ethical debate on functional rehabilitation. Mention should be made here of the Hastings Center report of August 1987 (A. L. Caplan, D. Callahan, J. Haas: “Ethical and Policy Issues in Rehabilitation Medicine. A Hastings Center Report”, special supplement, August 1987) and, most importantly, the international conference held on 23 and 24 June 1989 in Denver, Colorado (ed. B. Duncan, D. E. Woods: “Ethical Issues in Disability and Rehabilitation. Report of a 1989 International Conference”, published by WRF, W.I.D., R.I.).



What literature is available discusses a wide range of themes, from the now "classical" ones of consent, the right to information, and medical paternalism to the highly complex and general ethical issue of resource allocation.

Some of these themes are already a familiar subject of debate in other branches of medicine, but their significance for rehabilitation is different. Functional rehabilitation is generally a long-term, dynamic process and very often involves ethical questions which at times take precedence over purely technical and therapeutic considerations. The patient needs to be an active participant in the process of treatment, within a teamwork structure which involves the family whenever possible. For obvious reasons, we cannot summarise all the ethical issues connected with selecting and planning a rehabilitation programme here. Four points in the ethical debate would appear essential, however:

1. knowledge (full awareness on the part of the disabled person of the practical limitations of rehabilitation);
2. need (the scientific basis for the rehabilitative treatment);
3. benefit (the practical value of rehabilitation in general terms, which should yield an acceptable cost-benefit ratio);
4. consent (not in the strictly legal sense but essentially in ethical terms, i.e. the disabled person's full involvement in the rehabilitation process).

The key ethical issue in functional rehabilitation is the definition of the nature of rehabilitative treatment, which is far too complex to be classed with traditional therapies. On this point, we believe comparisons can be drawn with two major fields of modern medicine. One is psychoanalysis: not a therapeutic process in the traditional sense, but what may be defined as a dynamic process of cognition in which the relationship between analyst and analysand plays a decisive role. The other is drug addiction, and in particular the drug therapy community as a centre for rehabilitation. Here, medical treatment is intimately bound up with and ultimately subordinate to the essentially educational process which develops between staff and patient. The focus thus broadens from drug therapy to life skills. Functional rehabilitation, therefore, is basically a process of unlimited duration which is not exclusively medico-therapeutic in nature,

but includes a strong educational component linked to the urgent need to help disabled people plan for a future life commensurate with their expectations and residual psycho-physical capacities.

This also accounts for the need for close ties between functional rehabilitation and occupational integration. The choice and implementation of rehabilitative treatment must be closely geared to the development of residual abilities, primarily for the purposes of occupational integration. Therapy/rehabilitation, assessment and social and economic integration should be three successive and connected stages of the same process (the principle of continuity and unity). It should also be noted that rapid changes in the nature of employment have highlighted the need for a form of assessment based on a concept of the individual's overall relational abilities rather than job skills alone.

To conclude, mention must be made of the issue of resource allocation. It is our belief that assistance for disabled people must be regarded as an act of justice and not of charity. In other words, we believe that the general move to reduce health spending, by means of privatising the management of health services across Europe, must not be allowed to work to the detriment of the disadvantaged members of society, especially elderly and disabled people. Theoretical support for this stance, which is part of the general ethical debate, is to be found in Rawls's proposal (J. Rawls: "A Theory of Justice", 1971) of a society founded on two principles of justice, in which freedom and welfare have equal status: the principle of liberty and the principle of difference. Very briefly, liberty is held to have priority in the sense that it is one value which cannot be exchanged against another: degrees of freedom cannot be forfeited to increase other assets (economic resources, etc.). The second, or "maximin", principle dictates that the choice must fall upon whichever free social order delivers differentials in income and in the distribution of staple goods that will bring overall improvements to the conditions of the least well-off. This ethical obligation to foster intervention by the State in support of its weaker citizens contrasts with the approach of those theoreticians who advocate a "minimalist" State (R. Nozick, "Anarchy, State and Utopia", 1974)

where the concerns of laissez-faire individualism prevail over social considerations.

This does not mean, of course, that assistance for disabled people should be borne solely by the State: NGOs and non-profit-making organisations have an important support function, but they should not be a substitute for State intervention.

The issue of resource allocation is clearly one in which ethical questions must be seen in the wider context of the defence of human rights. This, in our opinion, is the key point which must be tackled and clarified at European and global level as the foundation for social policies over the coming years.

This brief review of the issues points chiefly to the complexity which would seem to be the dominant feature of contemporary ethics, especially if viewed in the broader perspective of human rights. Considerable progress has undoubtedly been made to date, but much remains to be done, and the interdisciplinary and international contribution of the participants in the HELIOS II programme could well prove vital.

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Mental health and people with learning difficulties

a new theme for an old issue

“Learning difficulties” are currently defined as reduced intellectual ability (IQ below 70) and a limited capacity for social adjustment, which become apparent during the formative years (up to the eighteenth birthday). The disability affects 1% to 1.5% of the population in all countries, with no real disparities between the eastern, western, northern and southern regions of the world.

Recent developments in care for people with learning difficulties

Over the last 20 years, care for people with learning difficulties has expanded considerably. Professional carers from all western European countries currently apply the principles of the Normalisation Movement, which promotes the social integration of people with learning difficulties and the normalisation of their lives. However, obstacles often arise along this path to normalisation, in the form of behavioural difficulties. Aggressive, self-destructive and destructive behaviour in particular are the most common grounds for institutionalisation.

Experts have gradually improved their understanding of these behavioural disorders over the last 10 years. In particular, it has been discovered that disruptive and disturbed behaviour is very often prompted by one or several underlying psychological (psychiatric) disorders (illnesses). Various researchers in a number of countries have found that these behavioural and psychological disorders occur in 30% to 50% of cases, i.e. three to five times more frequently than in the general population. In recent years, experts in various countries have become more aware that mental health problems are a genuine barrier to ensuring quality of life and well-being for people with learning difficulties.

Can a person with learning difficulties have good mental health?

The same criteria apply to disabled people as to non-disabled people regarding mental health, namely: physical health, a psychologically balanced development and adequate social interaction with the

environment. Learning difficulties are now no longer seen, as they were in the past, as an illness, but as a psychosocial development disorder affecting cognitive abilities in particular.

Scientists now think that learning difficulties are above all a quantitative development anomaly. The cognitive development of a child with a disability of this kind is slow and can stop too soon, so that his or her cognitive abilities develop to significantly below the level of an average child of the same age.

The qualitative development of disabled children is no different from that of their non-disabled counterparts. Development follows the same course through the same development stages as for children who are not affected. This is why the level of cognitive development of a person with learning difficulties is compared with the calendar age of an average non-disabled child. In an adult, an IQ of 70 corresponds to the level of development of a 12-year-old child, while an IQ of 50 corresponds to that of a seven-year-old child, and so on.

The personality development of people with learning difficulties, as well as their cognitive development, is compared with the development of non-disabled children. It is assumed that, as for non-disabled children, the cognitive faculties and personality of people with learning difficulties develop in tandem in a favourable environment and, in balanced psychological conditions, reach the level described above. If the cognitive limitations of people with learning difficulties are duly taken into account, they are quite able to engage in meaningful social interaction. They can



experience positive emotions such as love, happiness and trust, and can be at peace with both others and themselves. Therefore such people can, despite their disability, enjoy good mental health.

Psychological illness and learning difficulties

As mentioned above, psychological disorders are considerably more frequent among people with learning difficulties than among non-disabled people. That is put down to the various biological disorders, difficult psychosocial development and negative environmental influences which they must contend with. The psychological illnesses of people with learning difficulties are not seen as inherent in their disability, but as additional, secondary disorders. Recognising symptoms and establishing a psychiatric diagnosis can be difficult, however. Knowledge is currently inadequate in this field. Similarly there is a lack of specific expertise in the application of alternative methods of treatment.

Specialised mental health care for people with learning difficulties

There is no longer any doubt that adequate mental health care is necessary if people with learning difficulties are to achieve optimum quality of life. Carers require specific knowledge and skills in providing this care, because psychological health and illness is more complex in the case of people with learning difficulties than in that of the general population. Moreover, specific factors often play a role for disabled people. Unfortunately, it must be noted that to date mainstream psychiatry has demonstrated little interest in the

problems of people with learning difficulties. And average psychiatric expertise is not enough to cope with the specific problems involved. This is why experts in this field have called for the creation of specialised mental health services or centres for people with learning difficulties.

These centres should primarily be intended for research and the diagnosis, treatment, habilitation and rehabilitation of people with learning difficulties who have psychological and behavioural disorders. These centres should also provide training for carers.

At present, with the exception of the United Kingdom, no European country provides structured mental health care for people with learning difficulties. In some countries, such as the Netherlands, the issue of the mental health of people with learning difficulties is only just coming to the attention of a broader circle of professionals. In other countries, isolated attempts are being made at introducing and implementing these ideas in the health-care sector.

Recently the European Association for Mental Health in Mental Retardation was set up with the aim of supporting and promoting the ideas and practice of structured mental health care through international cooperation.

European Community projects such as HELIOS II can play a major role in developing this form of care, in particular with respect to bridging discrepancies between the various countries and pooling and increasing the expertise of carers.

Conclusion

People with learning difficulties have an inner world of experience which in qualitative terms is no different from that of non-disabled people. If their environment anticipates their needs and possibilities adequately, they can lead a psychologically healthy life despite their cognitive limitations. People with learning difficulties are more vulnerable to psychological and behavioural disorders than the population as a whole. Specialist mental health care is required to ensure proper habilitation and rehabilitation. We believe that this care is a precondition for the "normalisation" of these people's lives.

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At a clinical level, low vision or partial sightedness means reduced vision which cannot be improved through medical treatment and/or standard optical lenses. The remaining vision is usually expressed as visual acuity below 0.3 and/or a narrowing of the visual field to 20° and less. But low vision can also be determined by other factors such as reduced perception of contrast, light or colour.

Vocational training for low vision therapists

In functional terms, we speak of low vision where an individual finds it impossible or difficult to carry out his or her daily activities (at home, school, work or during leisure time) owing to reduced vision. Approximately 1% of the population has low vision, and the condition can affect children, adults and elderly people alike.

Low vision can take a variety of forms which are sometimes not fully understood by other people. For example, a person with a sharply narrowed visual field can read a newspaper, but cannot cross a road safely. Someone else might be able to walk and do housework, but be unable to recognise people in the street or read a menu in a restaurant.

Rehabilitation of low vision

Rehabilitation of low vision is intended for people who encounter problems in daily life on account of their visual impairment. Its purpose is to allow these people to be as independent as possible using specific tools (both optical and non-optical) and training techniques. Unlike in the past – when saving visual power was the favoured approach – the remaining vision is put to active use. Techniques for blind people which aim to compensate for the lack of vision, such as Braille and using a white stick, remain important but are no longer the only solution.

Institutes for blind people where only traditional techniques are taught have virtually disappeared. Nowadays these institutes' activities focus on coordinating educational support for children with low vision in mainstream education. Low vision rehabilitation and the increasing range of technical aids on offer has en-

hanced the training and employment opportunities of visually impaired people, and older people with low vision are able to lead an independent life.

Low vision rehabilitation is a cross-disciplinary activity. A comprehensive team of professionals (including ophthalmologists, low vision therapists, optometrists and opticians, mobility trainers, social workers, etc.), along with the family, volunteers and self-help groups and associations for blind and visually impaired people, work together with the person with low vision. The aim is to make the best possible use of the remaining vision (and/or compensatory techniques such as Braille), to improve the way people cope in daily life and safeguard their independence.

A rehabilitation programme consists of the following: examination of remaining vision; testing and adaptation of optical aids and training in how to use them; orientation and mobility training; adaptation of daily activities; social and psychological support; and integration into the mainstream education system and the labour market.

Low vision therapy

Low vision therapy has led to the emergence of a new profession, new rehabilitation methods and new specialist centres. Low vision therapists must be well trained, to guarantee a high standard of rehabilitation. In fact, at various levels, training or refresher training is necessary for ophthalmologists, opticians, therapists, educators, social workers and psychologists. These professionals have kept to the "blind people model" for years, and although they are open to new reha-

bilitation methods, training – where it exists – is usually inadequate.

Although the term "low vision" has been in use since the 1960s, professional training in low vision therapy dates only from the 1970s and 1980s. Sweden and the United States lead the field. In most European countries there is still no official or well structured low vision therapy training. In the framework of the HELIOS II functional rehabilitation sector, Working Group 6 is seeking to change this situation. This group deals with the problems of people with a visual disorder (partially sighted and blind people). Training has been selected as the most important working issue for 1995. Information about existing education and training programmes is in the process of being collected. It will then be examined with a view to developing a European minimum standard for training in low vision therapy.

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Debate

Deafness, hearing impairments and rehabilitation

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The degree of development of a given society has repercussions not only on the spectrum of diseases which cause hearing impairments and deafness, but also as regards opportunities for the individual, social attitudes and the resources available to reduce the impact of the impairment.

In the post-industrial societies in which we live, more and more people aspire to improved healthcare and a better quality of life. This influences the concept of the disability itself and lesser degrees of hearing impairment are being identified by patients, families and professionals. At the same time, technological advances are rapidly creating new possibilities and approaches for people with impaired hearing and language skills.

Awareness of the key importance of a broad concept of communication has grown across all age groups and among the various disciplines that deal with hearing impairment and deafness, influencing aspects such as early diagnosis, early intervention, education, careers guidance, technical aids, leisure activities and prevention.

Communication is an essential part of life. A rich and structured language is a fundamental resource for every individual. Spoken language is the most widely used by the population in general. Sign language is not inferior but is used in a more limited environment. The bilingual option is gaining more and more support as a means of improving the communication potential of deaf people in today's world.

Improved knowledge of hearing, as a result of technological advance, has significantly enlarged the possibilities of using residual hearing and has certainly opened up new prospects for present and future generations. But despite all this progress, the complexity of deafness is widely misunderstood and underestimated. The use of cochlear implants and hearing aids cannot be considered a mira-

cle cure for deafness. The integration of technical aids in planning for the long and difficult process of rehabilitation is more important than ever.

So much is happening in the field of rehabilitation for hearing impairments that a lot of the attention of the professionals should be focused on ensuring that they are well informed. This is essential if they are to offer sound advice to the patients and families who turn to them every day.

Information and decision-making increasingly rely on teamwork between the surgeon, the audiologist, the speech/language pathologist, the educator of hearing-impaired people, the psychologist and the social worker.

Patients and families need time, reassurance of our continuous support, and sound advice. The individual's possibilities and limitations with respect to the various options available, and the importance of central nervous system plasticity, should be openly discussed in preparation for an informed decision.

Now more than ever, communication and information transfer is needed between the professional world and the local deaf community, to clarify ideas and avoid misunderstandings, with the ultimate objective of improving quality of life for present and future generations.



Photo: John Van Gelder - Amsterdam



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Listen to deaf people with your eyes*

The functional rehabilitation society offers deaf people tries to make us behave like hearing people; there is a pretence at accepting us by putting deaf children into mainstream schools, and later in life putting us on the periphery of society, but when the realisation dawns that we have a different need, namely our own language – sign language – and our own culture, we are abandoned. The real rehabilitation of deaf people will come in the deaf community, where we should have been from our early days.

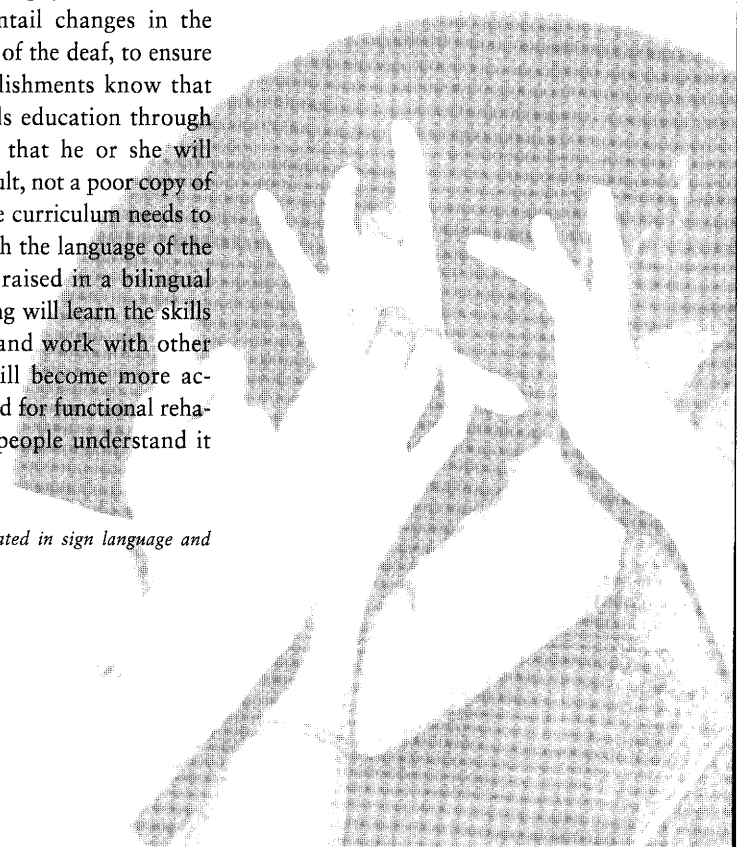
The label “linguistic minority” was given to us when society realised we were not matching the norms attached to the “disabled” label. What we want is what everyone wants – respect for us as individuals. Deaf people know that no matter how ingenious the technology, how brilliant the doctors, etc., and how appealing the idea of helping deaf people seems, the crux of the matter is that as long as deaf people exist on this planet there will always be sign language, and as long as sign language exists deaf people will have their own identity and common sense will prevail. We will always hear with our eyes.

We do not ask for much, we simply want to be ourselves, keep our identity, be accepted as people in our own right. If some of us have hearing and make use of it – fine; others have no hearing, and that is fine too. The hard-of-hearing community is different to the deaf community, but society expects us all to be the same. I cannot speak for hard-of-hearing people, but I respect them as a group, and hope that respect is reciprocated. For deaf people, relying on their eyes to listen, the need for support technology – subtitles, videos, fax machines, visiphones, etc. – is there.

We also need a revolution in education: a young deaf child should have complete exposure to a deaf cultural environment in the early formative years, so that the sense of identity and self-worth is established right from the beginning. Deaf history, for example, conveyed in the same carrier language that the deaf child is using – by deaf people who have the same viewpoint and have been through life in deaf schools. It is our past and we want it presented through our eyes, not always through the hearing perspective. There is a need for a full and recognised Deaf Studies curriculum, where subjects including English and any other spoken language are taught through sign language, so that the children feel that they are fully accepted, and are not being educated on the periphery of the hearing system.

All this will entail changes in the training of teachers of the deaf, to ensure that training establishments know that the deaf child needs education through sign language and that he or she will grow into a deaf adult, not a poor copy of a hearing child. The curriculum needs to be changed to match the language of the eye. Deaf children raised in a bilingual and bicultural setting will learn the skills they need to meet and work with other cultures, society will become more accepting, and the need for functional rehabilitation as most people understand it will become less.

* This article was dictated in sign language and then translated.



The European guides of good practice

One of the main objectives of HELIOS II is to change and improve the attitudes of the general public towards disabled people, and in particular those of decision-makers and professionals who may influence their lives.

One of the lasting and tangible results of the HELIOS programme will be a set of European good practice guides. Five guides will be produced, covering the following areas:

- Functional rehabilitation
- Integrated education
- Social integration
- Preparation for employment
- Employment

The guides will be based on the activities of the HELIOS programme. The role of Edinburgh's Telford College is to analyse the results of HELIOS activities and organise the information on good practice into clear and informative guides. It is important to emphasise that the guides will be based on existing good practice within the EU. They will not be wish lists or recommendations of ideal practice. Instead they are a place where examples of good practice drawn from various Member States can be set before a wider audience.

A specific list of primary sources of information for the guides has been agreed as follows:

- 1 Information from the 1993 activities of the HELIOS NGO sector (with the NGO sector deciding which information

arising from its 1993 activities can be incorporated in the guides).

- 2 The summary conclusions of the NGO conferences (Europrogramme annual reports).
- 3 The reports summarising the conclusions of the end-of-year seminars of the exchange and information activities (1994 and 1995), plus reports from study visits.
- 4 The expertise of the HELIOS jury members and the activities of the HELIOS competition winners.
- 5 Information from the European Disability Forum, the Advisory Committee and the six working groups.
- 6 Information resulting from cooperation with relevant international organisations, particularly UN agencies (UNESCO, the WHO and the ILO), the OECD, the Council of Europe and the ECMT (European Conference of Ministers of Transport).

In addition to providing specific examples of good practice, information from these sources will be analysed to identify the common general principles of good practice. Highlighting these principles of good practice will be a very important function of the guides.

The target readership will be people relevant to each field who are in a position to influence future practice. Some specific suggested audiences for the guides are as follows:

- Functional rehabilitation – healthcare institutions and rehabilitation centres
- Education – educational institutions (management/staff/students)
- Social integration – decision-makers, professionals, families of disabled people and information brokers
- Preparation for employment – employers and trainers
- Employment – employers and employees

The main content of the guides will be in three sections: an introduction common to all guides; a section looking at principles of good practice in the sector; and a section using case studies to describe specific examples of good practice in action.

The guides are being drafted by Edinburgh's Telford College (Scotland, UK), in close consultation with the European Commission, assisted by the HELIOS Team of Experts.

Development of the guides is already under way, and will continue throughout 1995 and 1996. The first draft will be presented for comments to members of the HELIOS advisory bodies in early 1996. The guides will be published in all the official EU languages and launched at the December 1996 conference, when prizes will be awarded to the winners of the 1996 HELIOS competitions.

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NGOs

in the mental

European Network of Users and Ex-Users in Mental Health

The European Network of Users and Ex-Users in Mental Health was set up in 1991, thus adding a new name to the list of organisations involved in the European Disability Forum.

“It is very important to realise that you are not the only person to know what it’s like to be labelled a psychiatric patient”, says Jan Dirk van Abshoven, the retiring secretary at the European Desk. The “Desk” is the information centre of the European Network of Users and Ex-Users in Mental Health. Contacts – both national and international – among patients receiving or having received psychiatric care date back to long before the network was set up. But it was in the early 1990s that the need for more permanent exchange truly emerged. Gathering information at European level makes it possible to disseminate experience locally as well as throughout Europe. At the same time, more cohesion and cooperation is required between the local and European authorities – simply because decisions taken in one place increasingly have an impact elsewhere.

Psychiatric treatment

The “psychiatric patient” label casts doubt on the person’s ability to take reasoned decisions. This often results in other people taking responsibility for decisions on behalf of the individuals concerned, who are no longer consulted. Decisions are made and acted upon without consideration for what they might think. However, since the 1980s an increasing number of aids have been developed to ensure that the people concerned can make their voices heard, at the very times when they would previously have been ignored. In 1989, for example, users in Wales developed a “crisis card”. Also, a concept originally developed in the United States and known as the “psychi-

atric testament” was further developed and implemented in Berlin. This is in effect a “contract” in which the person sets out what may and may not be done should psychiatric intervention be necessary, before the situation arises.

Psychiatric treatment nearly always involves psychopharmaceuticals. More information is needed about these “medicines”, and in particular about their side effects. Reports in the United Kingdom of a possible link between fatalities and the Clozapine/Laponex drug prompted a request for the University of Utrecht (Netherlands) to undertake a literature search. The research report was published in June 1994.

More information is also needed on electroshock therapy, which many people would describe as maltreatment rather than acceptable treatment. Clear information must be the sole basis for any informed consent – a premise which is gaining increasing acceptance among those responsible for medical intervention and treatment. The Second European Conference of Users and Ex-Users held last year in Denmark concluded that electroshock therapy should no longer be used for children and other minors. It also called for all forms of enforced treatment to be banned. Another proposal was the publication of a brochure on treatment which does not involve medication.

Non-medical alternatives

An alternatives task group was set up in 1991 to prepare the publication of a Directory of Alternatives. The project was coordinated from Italy, where there have been many experiments with alternatives

to mainstream psychiatry in the form of work cooperatives. The directory is due to be published shortly. A working party on legal protection and compensation has also been set up, and has started to meet. Legal issues are probably the greatest concern of many people.

Structure

The European Network of Users and Ex-Users initially had a flexible, bottom-up structure, with the working parties coordinating their activities through a coordination group. A year ago, the elected management committee assumed responsibility for coordination and decision-making in the network. The next conference, at which policy will be further developed, is to be held in the United Kingdom in 1996. The *European Newsletter* exchanges information on views and measures. It is published in Helsingborg (Sweden).

Psychiatry and human rights

Officially, human rights apply to everyone – but in some situations they are very difficult to invoke. And legal protection for psychiatric patients varies greatly from one country to another. The January issue of the newsletter carries the text of the Council of Europe’s recommendation on human rights and psychiatry, with comments from the network managers. The recommendation sets out criteria which lay a common foundation, beyond these national differences. The network wholeheartedly welcomes the approach taken in Recommendation 1235 and Resolution 1029, in which the Council of Europe considers psychiatry from the angle

health sector

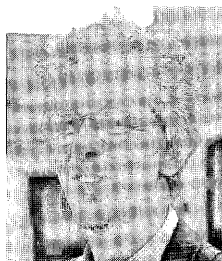
of human rights rather than as a purely medical issue. The network management committee also supports the Council of Europe's call for psychiatry to be subject to independent inspection. Network member organisations are invited to lobby their own governments to implement the recommendation.

What next?

"Our most important concern for the future is continuity – simply to ensure that the European network continues to exist. Our views must remain on the agenda. This is not an easy task since most of the work is carried out by volunteers, who often have other occupations. We must continue to strive for the recognition of organisations of users and ex-users, both nationally and at European level. We take

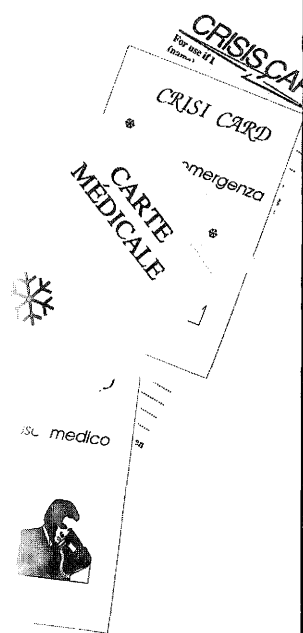
encouragement from the fact that a number of meetings receive financial support from national governments and from the HELIOS programme". Such was the message from Jan Dirk van Abshoven, who handed over his responsibilities at the European Desk to Rinus de Groot on 1 June.

Wouter van de Graaf
Amsterdam



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The European Regional Council of the World Federation of Mental Health (ERC-WFMH)

One person in 10 is known to have a mental illness. 62% of these have psychoses, depressions and major psychological problems. Mental illness kills four times as many people as road accidents. It is five times more common than learning difficulties, three times more than cancer and 3,000 times more than AIDS. 99% of people with mental illness live in the community.

These brief statistics indicate the impact of mental illness on modern society. Yet it remains the poor relation throughout Europe. Improving mental health will depend substantially on the progress made on combatting poverty, social exclusion and the taboos which surround mental illness. The rising tide of long-

term unemployment, violence, immigration, suicide, attempted suicide and homelessness, the breakdown of family structures and the emergence of a multicultural society all call for active involvement on the part of the ERC-WFMH.

The ERC-WFMH* is responsible for developing a policy on mental health at

European level. It is the only cross-disciplinary organisation to unite psychiatrists, psychologists, social workers, nurses, doctors, managers, lawyers, voluntary workers, families and people with mental illness in a common cause: improving the mental health and quality of life of people with mental illness in Europe.

NGOs

in the mental health sector

Cooperation with the organisations involved in various European countries enables us to tap into a broad network of resources. One of our aims is to set up a European partnership to promote dialogue not only between users, families, workers and managers, but also among policy-makers and officials responsible for mental health services. In addition, we seek to support new initiatives in the developing world and in countries which have recently undergone major political upheavals (in central and eastern Europe).

As part of our coordination, within the HELIOS II programme, of the psychological and behavioural disabilities sector, we set up the forum of European NGOs working in the mental health field to frame a common policy in relation to the European Parliament, the European Commission and the various authorities responsible for mental health in Europe. The forum comprises AESMEAF (the European association for cross-disciplinary practices on mental health for children, adolescents and the family), ALZHEIMER Europe, CEDEP (the European committee on law, ethics and psychiatry), EUFAMI (the European Federation of Associations of Relatives of the Mentally Ill), the European Network of Users and Ex-Users in Mental Health, Europsy-Rehabilitation, the IFS Eurogroup, FERMENT (the Foundation for European Reforms in Mental Health), CEFEC (the Confederation of European Firms, Employment Initiatives and Cooperatives for the Psychiatrically Disabled), the ESMHD (European Society for Mental Health and Deafness) and IFOTES (the International Federation of Telephonic Emergency Services). These European organisations are all complementary, and all share the firm belief that priority should be given to legislation and users' rights. In legal terms, the issues concerning the status of people with mental health problems are twofold: compulsory hospitalisation and legal protection.

The negative image and taboos attached to mental illness remain a major challenge. The prejudice and alienation people with mental health problems have experienced since time immemorial still influence social attitudes today. The onus is on us – users, families, professionals and managers of mental health services – to reject that discrimination. We therefore call on all national and international decision-makers to lend us their recognition and support, to ensure that people with mental illness are given a fairer deal. In partnership we can make our voices heard. United — in Europe — we stand...

Josée Van Remoortel

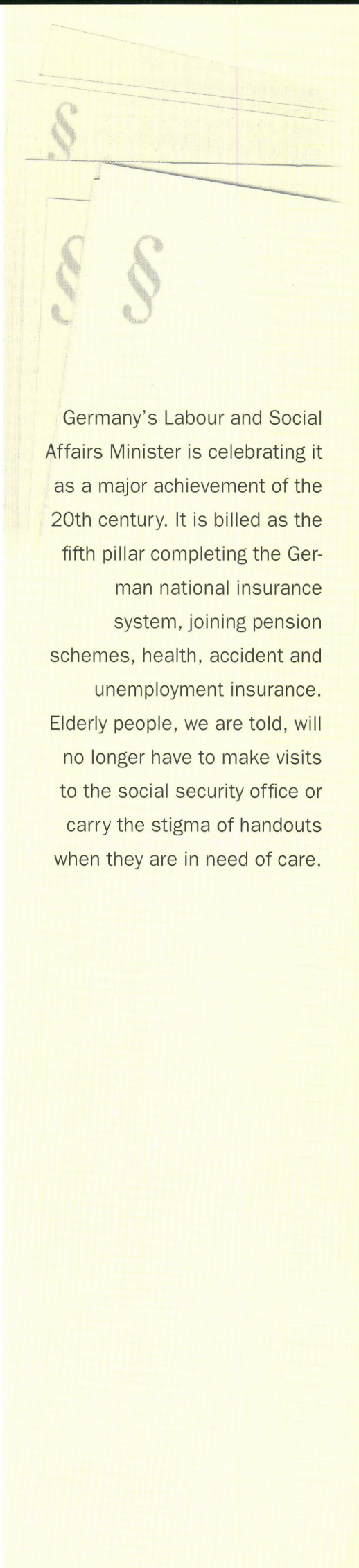
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** For further details concerning the responsibilities of the ERC-WFMH within HELIOS II and its status with international organisations, see our profile in HELIOSCOPE No. 1, summer 1994.*



Germany's Labour and Social Affairs Minister is celebrating it as a major achievement of the 20th century. It is billed as the fifth pillar completing the German national insurance system, joining pension schemes, health, accident and unemployment insurance. Elderly people, we are told, will no longer have to make visits to the social security office or carry the stigma of handouts when they are in need of care.

Care insurance

reform or nightmare?*

German social assistance legislation had previously succeeded in cultivating the fragile flower of local government financing – albeit means-tested – for personal assistance services to disabled people. Where family members could not provide care, disabled people could organise their personal assistance themselves and their costs were refunded. They were also entitled to an attendance allowance. Since the care insurance law came into force on 1 January 1995 and benefit payments started in April, all that has changed.

Contrary to the general principle applied in social security law, whereby the level of contributions is pegged to benefits required, here the principle applied is that of balancing contributions, i.e. the care insurance funds may conclude contracts on the type, scope and payment of benefits only where the income from contributions is sufficient to meet the costs. Contracts in excess of income are void. In other words, it is not benefit levels which determine contributions, but contribution levels, laid down by law, which determine the benefits available. Care insurance benefits are therefore intended only to “supplement care provided by family, neighbours and voluntary organisations”. Depending on the level of care required, benefits in kind worth DM 750, DM 1,800 or DM 2,800 a month may be provided, where the services are furnished by a recognised care provider. Where individuals make their own arrangements for care, this falls to DM 400, DM 800 and DM 1,300 respectively. To qualify for care level I, the disabled person must require basic care for at least 1 1/2 to three hours a day and home help several times a week, for care level II three to five hours’ care a day and for care level III round-the-clock care – i.e. night time included. In hardship cases (e.g. patients in the terminal stages of cancer), an exceptional allowance of DM 3,750 a month may be awarded. This higher rate may be

paid to a maximum of 3% of people in need of level III care. Once that ceiling is reached, other eligible claims will be automatically rejected. This is clearly in breach of constitutional guarantees.

Services for disabled people who require a higher level of personal assistance are not paid for under this law; instead these people have to apply for supplementary welfare benefits. The system is further restricted by changes in the concept of care. For example, only services which promote mobility within the home now come under the heading of care. Participation in activities outside the home is no longer one of the needs to be financed under care regulations. Whereas in the past all assistance associated with care (e.g. home help) was seen as part of integrated service provision in law, the care insurance funds now differentiate between these services. In practice, that means, for example, that health insurance funds’ medical officers now approve only 1 1/2 to three hours’ care a day at level I for disabled people who previously received seven hours.

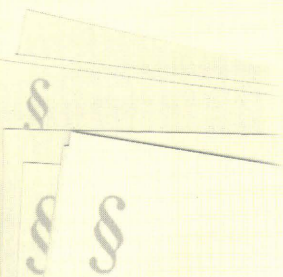
The new law may assert the right of the individual to lead an autonomous and independent life, but a far lower level of financing – only equivalent to the attendance allowance – is provided for assistance arranged for by disabled people themselves. Moreover, a committee amounting in effect to a board of inspectors is to review the care situation at least twice a year at care levels I and II, and at least four times a year at care level III. This is financed out of the pocket of the person receiving care. Disabled people who employ their assistants and want to conclude agreements with the health insurance funds are not recognised as contractual partners. Care services performed by a qualified nurse are a prerequisite for a contract of this kind. Clearly, only medical care and not personal assistance organised and monitored

by the consumer is eligible for financing – making independent living with personal assistance virtually impossible.

The priority given to outpatient over inpatient care under previous legislation is now limited. Whereas up to now institutionalisation was an option only when domiciliary care was not possible or could not be organised, now disabled people have merely the “right to stay as long as possible in the home environment”. It remains to be seen whether this wording will be sufficient to prevent people being put into homes where that is the cheaper option. It is not even clear whether this right will be maintained under the new legislation. It is clear even now that the obligation of the federal Länder to maintain an adequate care structure is being interpreted primarily as a duty to build more nursing homes, residential schemes and institutions providing partial inpatient care. Instead of improving conditions for disabled people outside the confines of homes and institutions, the new law encourages a major construction programme in the residential care sector, because it has occurred to virtually none of the German Länder to use the sometimes huge savings to extend outpatient services. Thus this law further promotes the segregation of disabled people. Already, over 80% of expenditure on care is confined to inpatient structures.

At the same time, the new regulations further tighten the rules for assessing care requirement levels. Disabled people who, in the past, were in the top category for care under social assistance legislation, are now frequently classed no higher than level II. New applicants are placed directly in a lower category. Once the ceiling on benefits in kind is reached, disabled people will no longer be entitled to an attendance allowance from the care insurance fund and only a third of the attendance allowance is payable by the social services, as against half in the past. The new law limits the shrewd scheme





Care insurance

reform or nightmare?*

whereby, with a combination of care provision by the social services and assistance organised by the disabled person, at least half the attendance allowance remained in the possession of the beneficiary: that sum has now been cut back to a third. Moving to another country presents a particular problem. Under German social legislation, entitlement is suspended while the disabled person is abroad. This even applies to the EU. Particularly in view of Council Regulation (EEC) No. 1408/71 of 14.6.1971 on the application of social security schemes to employed persons and their families moving within the Community, it cannot be acceptable to limit the freedom of disabled people to live where they choose within the EU. Even when employees in Germany have had a claim accepted and have gone to live in another EU country after becoming in need of care, the claim should not be considered void unless their benefit entitlement is higher in the host country. Equally, it remains to be specified in the Council regulation whether periods of care insurance abroad should be taken into account when assessing a claim. From 1996, care insurance claimants must have at least one year's contributions to their credit. A requirement of five years' contributions is to be phased in by the year 2000. If periods of insurance in other EU countries are taken into account when calculating pension entitlement, the same must apply to care insurance.

Who stands to gain by care insurance?

The only people who stand to gain by the care insurance system are those in need of care whose income or savings took them over the limit for benefit entitlement under the old rules. Everyone else in need of care will see sharp cuts in benefits over the medium term. The municipalities are the clear winners: a large share of their costs are shifted to the insurance contribution burden. By the same token, em-

ployers benefit more from the cancellation of a public holiday than they lose on their contribution to the system. It is therefore the people paying insurance contributions and those receiving benefits who have to foot the bill for care insurance, and them alone. But the greatest backwards step is the ideological move towards a medical concept of care. What consequences that will have for entitlement to personal assistance is not at all clear at this stage. But there must be fears that the new law is clawing back the hard-won right of disabled people to lead an independent life with personal assistance. There are still battles ahead if we are to secure that right.

Horst Frehe

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* This is a shortened version of Mr Frehe's article. The complete text is available from the HELIOS Team of Experts, HELIOSCOPE editorial office, av. de Cortenberg 79, B-1040 Bruxelles.

The HESTIA Towards EMPLOYMENT study, carried out as part of a strategy of closer links between the European Union and the central and eastern European countries (CEECs), was designed to gather general information on the integration of disabled people in the Czech Republic, Hungary, Poland and Slovakia, along with practical details on measures and experiments in the field of vocational training and employment.

The purpose of the HESTIA Towards EMPLOYMENT study was to collect general and practical information on disabled people from all those involved at national and local level – institutional partners, professionals, NGO representatives and disabled people themselves. The study was carried out over a period of six months by the Centre de Réadaptation professionnelle et fonctionnelle (CRPF) of Nanteau-sur-Lunain (F) and the European NGO Rehabilitation International – European Communities Association (RI-ECA). It focused on two areas:

- the institutional, legal and social context of the integration of disabled people in the Czech Republic, Hungary, Poland and Slovakia;
- vocational training and employment systems, measures and practices for disabled people in these countries.

The HESTIA Towards EMPLOYMENT study

Each of these four countries has its own set of issues to contend with, but all four are in a state of flux. Institutions and provisions are changing, new legislation is being enacted, fresh initiatives are emerging, and needs and priorities are evolving accordingly. The HESTIA study provides a snapshot of the current situation and is intended to point up major trends. The report will form the basis for a debate on the resources and cooperation measures required specifically for the integration of disabled people. The following areas and forms of cooperation have been identified for the short and medium term.

Cooperation: focuses...

The main priorities are increasing cohesion between the various stages of the social and economic integration process, developing a vocational training system geared to national needs and finding an alternative to certain declining structures. There is a clear desire for cooperation. On employment, however, the advantage of cooperation is not always obvious, since the main concern of businesses is naturally to maintain production levels and find new markets in order to retain their staff, non-disabled and disabled workers alike. Nonetheless, a number of sheltered workshops have expressed a desire to visit similar establishments in western Europe to compare sectors of activity and management and production methods.

...and forms

The main forms of cooperation called for are transfers of know-how, the pooling of experience, training for professionals, and assistance for the development of infrastructure and new organisations and purchases of equipment. Both bilateral and multilateral cooperation is sought with counterparts either in European Union countries or in other CEECs. Proximity and cultural and linguistic affinities will be important factors in choosing partners. Several respondents also called

for documents to be translated into English and Russian to facilitate crossborder transfers of know-how.

The move to cooperate and pool positive experience is prompted by the wish not only to open up to the West but also to avoid repeating inconclusive experiments or choosing short-term solutions. A number of respondents said that what they were looking for were innovative ideas which were or could be tailored to their specific circumstances.

NGOs in particular stress the need for:

- information exchange through access to newsletters, other publications and the HANDYNET information system;
- more information on European projects they can take part in;
- participation in seminars and discussion groups;
- the development of practical initiatives and projects, together with NGOs or businesses in the EU;
- the cofinancing of initiatives;
- financial support for participation in international events (governments often finance only national events).

The NGOs expressed a preference for cooperation in the field of social integration, with functional rehabilitation, human rights and early assistance roughly tying for second place.

The HESTIA study has shown that those active in the disability movement in central Europe are eager for involvement in information exchange, study visits and analysis of the comparative merits of various systems. Measures over the short term could include extending European NGO representation in the framework of the HELIOS II programme to include

counterparts in the CEECs, disseminating activity reports and other programme publications and opening up access to HANDYNET. In the medium term, if, as is hoped, an exchange programme along the lines of HELIOS II is maintained, the various parties to the rehabilitation process could play a full part in activities.

Also worthy of mention is the interest expressed in participating in practical and innovative transnational projects. Current Community programmes go some way towards meeting this demand.

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The HESTIA study will be available in English, French and German as of November 1995 from the European Commission, DG V/E.3, Integration of disabled people division, rue de la Loi 200, B-1049 Bruxelles.

HESTIA

Strategies for increasing cooperation with central and eastern Europe

The HESTIA study, initiated and financed by the European Commission (DG V/E.3), clearly demonstrates the benefits and importance for the EU and central and eastern European countries (CEECs) of stepping up the exchange of information and knowledge on disability policies.

To date, cooperation between the European Union and the CEECs in this field has largely been limited to initiatives under the PHARE programme. The latter countries could not, therefore, take part in multidimensional exchange programmes at Community level such as HELIOS II, despite repeated expressions of interest.

This is set to change, with current political developments expected, in the medium term, to take the countries concerned into the European Union. On this point it should be recalled that, at its meeting in Copenhagen in June 1993, the European Council agreed that those CEECs which have concluded an association agreement with the European Union (the associated countries) may join the Union as soon as they are in a position to meet the political and economic obligations membership implies.

The associated countries at present are Poland, Hungary, the Czech Republic, Slovakia, Romania, Bulgaria, Estonia, Lithuania and Latvia.

As part of the development of a global strategy leading to accession, the European Council has invited the Commission to submit proposals with a view to opening up a number of Community programmes to the associated countries, along the lines of the measures already implemented for the EFTA States.

Accordingly, in addition to the Community programmes already established specifically for central and eastern Europe (PHARE, TEMPUS, COPERNICUS, etc.), the associated countries have begun taking part in a number of Community programmes, in particular under the third framework programme for research and technological development. And the LEONARDO, SOCRATES and Youth for Europe programmes are also due to be extended to include these countries.

Moreover, although no action has yet been taken to this effect, the associated countries could also participate in programmes relating to social and health policy.

Guidelines on procedures and arrangements for participation were adopted by the Council on 27 July 1994. It is now up to the Association Council, at the request of the country concerned, to decide on practical arrangements and conditions. In principle, associated countries are expected to cover participation costs, but the Union may provide top-up funds if necessary.

Although the procedure is probably too protracted for the associated countries to take part in the current HELIOS II programme, which runs until the end of 1996, their participation is an eventuality to be borne in mind for the programme's possible successor. That is why this aspect was considered in the framework of the Commission's consultation exercise on the future of the programme.

The combined findings of the HESTIA study and the consultation exercise will provide valuable information in preparation for the constructive participation of the associated countries in any new Community action programme.

Bernhard Wehrens
European Commission
Head of Division
"Integration of disabled people"

The UN standard rules : a new instrument for full participation

A message from Bengt Lindqvist, UN Special Rapporteur of
the Commission for Social Development on Disability

As you probably know, in December 1993 the United Nations adopted a new instrument entitled the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. The rules were drawn up in response to a request from the international disability organisations for stronger leadership from the UN on improving living conditions for disabled people.

I am often asked what is really new and different about these rules compared with the World Programme of Action concerning Disabled Persons, adopted in 1982. Well, there are some significant differences. The rules are more concise and more clearly structured. They are based to a greater extent on a human rights perspective. The rules address governments much more directly and, perhaps most importantly of all, they provide for a monitoring mechanism to further their effective implementation.

If you look for the most important contribution of this new UN document you will, in my opinion, find it in the way the philosophy of "full participation" is outlined. Based on a human rights perspective, the rules describe what has to be done to make it possible for persons with various disabilities to take part on fair and equal terms in the activities of the society they belong to. Let me quote paragraph 15 from the introduction to the rules: "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."

All of us who have disabilities are aware of such obstacles preventing us from leading a normal life. Sometimes they are very concrete, such as staircases and narrow doors for people in wheelchairs, books and newspapers which are not accessible for blind people, or when the language of the classroom teacher or the private doctor cannot be understood by a deaf person.

In other cases, the obstacles may be much more difficult to identify. This is often the case for people with chronic diseases or mentally retarded people. Nevertheless, the obstacles are there and these groups are prevented from full participation.

Working towards increased participation involves identifying and removing such obstacles. The standard rules are quite clear on the issue of responsibility: "It is the responsibility of States to take appropriate action to remove such obstacles" (end of para. 15 of the introduction). This, of course, brings us to the question of what action should be taken to tackle the remaining obstacles. The answer is that we need a whole range of measures. Reports are now coming in about new measures such as the establishment of a post of disability ombudsman or special high commissioner on disability, or a centre for equal opportunities – all new social institutions created to monitor the implementation of standard rules policies. The most common question I

hear is: to what extent should we rely on legislation, and what kind of legislation would be the most effective?

Here too, new developments are being reported regarding rights legislation and initiatives for anti-discrimination laws. The current debate on including disability issues in a broader non-discrimination legislation within the European Community is highly relevant in this context.

The standard rules came into existence in order to speed up development towards full participation for disabled people. I hope that all nations, including the 15 members of the EU, will use the opportunity offered by the UN standard rules to develop their disability policies. This should be a challenge for governments, the private sector and organisations of and for disabled people.

Platform of European Social NGOs

The European Disability Forum is one of 12 networks which currently make up the Platform of European Social NGOs. The platform has been meeting on a regular basis since the NGO Forum on Social Policy organised in April 1994 to respond to the Green Paper on social policy.

It is an informal structure, which has been set up to enhance cooperation among a broad range of European organisations working in the field of social policy, and to pursue common interests.

Recent work includes the preparation of a joint position on the Medium Term Social Action Programme 1995-1997, which outlines ways in which the European Commission plans to implement commitments made in the White Paper on European social policy. The platform's joint position records the need for the following principles to be translated into action:

- the interdependence of economic and social policies;
- social protection and solidarity;
- the involvement of all Union citizens in the process of European construction and the role of the NGOs that represent them.

This, the joint position states, will ensure:

- A social policy encompassing the whole population and not only workers and their families. The 1989 Community Charter of the Fundamental Social Rights of Workers must be broadened to all citizens, including legal residents from non-EU countries.
- A social policy which, beyond the fight against exclusion, aims at improving the wellbeing and solidarity of the whole population. While recognising that combatting poverty and exclusion is an important element, it must be part of a broader context to avoid the emergence of a dual society in which the number of people excluded will continue to increase.

- The development of an integrated rather than a sectoral approach to social policy, which is not limited to placing the rights of young people, women, older people, disabled people, etc., on an equal footing, but integrates a family dimension, in which the diversity of family models is respected.

The joint position also reiterates the potential and value of collective work by the platform, whilst respecting the specific objectives of individual networks in relation to their respective target groups – and specifies that each network should be given the opportunity to be consulted in its own right in relation to its particular sphere of activity.

In the communication on the social action programme, under the section "For a more active society", reference is made to a European Forum on Social Policy, to enable voluntary and other representative organisations to be consulted on a wide range of social issues. The first of these meetings is scheduled to take place in spring 1996.

The Platform of Social NGOs wishes to be seen by the Commission as a partner in the preparation and organisation of this forum. Particular concerns relate to the selection of themes for discussion, innovations and structures for meaningful consultation with NGOs beforehand and during the follow-up, and the scale of the meeting with a view to ensuring optimal impact. The platform has submitted a proposal to the European Commission concerning its input to the preparatory work.

Another priority for the platform is the intergovernmental conference in 1996. An outside expert has been appointed to draft a joint paper outlining common ground between platform members concerning the issues to be addressed at the intergovernmental conference. This will examine the need for a clause on non-discrimination, the need to boost the social dimension of the EU, the need to move towards a genuine people's Europe, and the importance of democracy and transparency in decision-making.

Other networks are:

- the European Anti-Poverty Network (EAPN)
- the Youth Forum of the European Union
- the Confederation of Family Organisations in the European Community (COFACE)
- the European Federation of National Associations working with the homeless (FEANTSA)
- the European Women's Lobby (EWL)
- the Migrants' Forum of the European Union
- EuroLink Age
- Mobility International
- Le Mouvement International ATD Quart Monde
- the European Social Action Network
- the European Forum for Child Welfare

The international classification of impairments, disabilities and handicaps

The international classification of disabilities, drawn up in the early 1980s on the initiative of the World Health Organisation (WHO), was largely designed by Professor Peter Wood of Manchester University.

The European Disability Forum, through its working group on the White Paper, recently presented its response to the White Paper on social policy and the social action programme to Mr Larsson, newly appointed Director-General of DG V. The response focused on the need for a legal base for non-discrimination legislation, the implementation of the UN standard rules at EU level, a strengthened consultative body modelled on the European Disability Forum, and access for disabled people to all Community programmes, measures and initiatives. It also examines the commitments on mainstream social policy contained in the White Paper and that document's relevance for disabled people. Copies of the response are available from the European Disability Forum, av. de Cortenberg 79, B-1040 Bruxelles.

A report on assessing disability was published in 1987 with a view to developing vocational rehabilitation measures, further to the "partial agreement" in the social and public health field signed by 10 countries in 1959 under the aegis of the Council of Europe. Committees of experts were requested to produce preliminary studies in preparation for resolutions on the matter.

The Council of Europe accordingly set up the committee of experts on the application of the international classification of impairments, disabilities and handicaps in 1989. The committee's remit is to analyse the main fields of application of the classification, which are as follows:

- rehabilitation work
- surveys and the collection of statistical data
- mental health
- the assessment of vocational abilities
- the assessment of technical aids
- applications of the concept of handicap given in the classification
- mental retardation
- paramedical professions
- policy and planning

Three other areas are still being studied:

- elderly people
- measures to enable people with impairments to remain in the community
- the education of disabled children

These studies, carried out between 1989 and 1995, have in particular enabled critical assessment of the classification. While the sections on impairments and disabilities were broadly welcomed, some reservations have been expressed regarding the

section on handicaps. The classification is not applied to disabled people. Rather, it seeks to clarify the concepts of impairment, disability and handicap.

In more general terms, it is regrettable that the classification is not more widely known. The Council of Europe is preparing a workshop for 1996 in conjunction with the European Commission and the World Health Organisation with a view to improving the dissemination of information, in particular for disabled people. The event will be an opportunity for NGOs belonging to the European Disability Forum to voice their opinions on the classification and collaborate with the committees of experts on the concepts and their definitions, and the use and value of the tool for statistical and vocational assessment purposes – two themes jointly selected by all those involved.

Josyane Pierre
HANDYNET Coordinator
HELIOS Team of Experts

Mainstreaming disability in EU programmes

News from the Disability Intergroup in the European Parliament

Last year, the Disability Intergroup successfully proposed amendments to make new resources available within HELIOS for the European Day of Disabled People and for NGOs' newsletters, and allocated 65 % of the resources for HORIZON to disabled people.

This year, the Commission's new social action programme contains a welcome commitment to ensure that disabled people can access all relevant Community programmes. However, despite aims to "mainstream" disability policy, disabled people have to look to HELIOS, HORIZON, TIDE and a programme on sport and disabled people administered by DG X for any funds.

MEPs on the Disability Intergroup are actively trying to ensure that disability is mainstreamed by proposing amendments to a number of other programmes. Mary Banotti, MEP (Vice Chair of the Youth, Culture, Education and Media Committee), has proposed that disabled people should be able to access programmes such as the arts programme KALEIDOSCOPE, and that the programme promoting the use of less widespread languages and cultures should include sign languages. Moreover, mainstream informa-

tion and communication programmes should specifically ensure that disabled people's information needs are met. Similarly, Richard Howitt, MEP, will be actively trying to ensure specific mention of disability within some development and regional policy budget lines. The Disability Intergroup will also be making representations to try and improve access to the European Parliament for disabled people, including the Parliament's own information and communication policy.

Diana Sutton

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Erratum

We must apologise for a major error in the article "NGO definitions of Independent Living" in *HELIOSCOPE* No. 4. The penultimate column, on peer counselling, of the English version states that: "Central to any understanding of Independent Living are the management of paid personal assistance services by disabled people themselves, and the education, or perhaps **conditioning**, of disabled people..." This should have read "**deconditioning**". The author of the article was certainly not suggesting that disabled people need conditioning or brainwashing. This communication error in the English original may have resulted in confusion in the other language versions. Again, our apologies.



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