

HELIOSCOPE

A young girl with a prosthetic hand is shown operating a sewing machine. She is wearing a patterned sweater and a dark dress with a floral pattern. The background is a warm, yellowish light. The girl's face is partially visible, looking towards the camera with a slight smile. Her prosthetic hand is holding a black ball, which is part of the sewing machine's mechanism. The overall mood is one of focus and achievement.

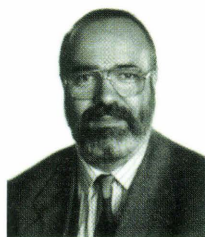
QUARTERLY - SUMMER 1995 - No. 4

**Social integration
and
independent living**

**Human rights:
the concept of equality**

The HANDYNET system

e d i t o r i a l



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independent living = capacity + aids

All citizens have a right to an independent life. A right to decide on their lifestyle for themselves, in an open society.

In practice, this right basically implies that each individual should be enabled to make the most of his or her capacities and that a range of aids should be identified which, by means of a policy of positive discrimination, can offset any disadvantages, thereby ensuring genuine equality of opportunity.

We all need some kind of aid at various stages in our lives. Short-sighted people see with the aid of glasses, and the translation which makes this text available in every Community language is an aid too. Yet no one would think to label a short-sighted person, or a German who does not happen to understand Spanish, "disabled". We must reject the assumption that we are all disabled, and rather think of ourselves as free citizens with diverse requirements for achieving independent living. We should avoid making a distinction between "ordinary" and "special" aids, and "cheap" and "expensive" ones, and supply them on the sole basis of individual needs. Let us also do away with the invisible but sinister barrier of segregationism in the guise of economic sense, which conveniently overlooks the fact that measures for disabled people serve society as a whole and, besides upholding the principle of equal opportunities, contribute to generating jobs and wealth throughout all the Member States.

The principle of the right to independent living should apply not only to personal but also to family and social life, and affirmative action is needed in these three areas. Measures could include assistance with everyday life, accommodation alone or with the family, and the accessibility of buildings. The successive stages in the life of each individual should also be considered when developing appropriate programmes and services. At first, we all need family support, before moving on to the world of education and training which will prepare us for working life, and eventually earning an income and making our own decisions in the three areas of our lives mentioned above.

Independent living for disabled people in Europe

In a European Union which is culturally, socially and economically diverse, independent living for disabled people also takes a variety of forms. Let me illustrate this point with the metaphor of the glass which is either half empty or half full. It is half empty because we still lack a genuine European social policy guaranteeing equal access to independent living. And it is half full because this very diversity enriches the process. It allows us to pool experience, find out about methods used elsewhere and, if they are more efficient, incorporate them into our own daily practice. If we also select examples of good practice, we will be in a position to provide the various Member States with useful pointers for their policies to promote independent living for disabled people.



The work carried out under the HELIOS I programme and the substantial increase in exchanges expected under HELIOS II could make a major contribution to improving practice at local level and identifying guidelines for suggestion to the various Member States.

Our practical experience over recent years has shown the tremendous role of work at grass-roots level in achieving independent living for disabled people. Many innovative initiatives are undertaken locally, and are often managed by local NGOs with financing from various public administrations.

The goal of independent living for disabled people as for the rest of the population – and indeed the very process of European integration – lies some way ahead. The focus is shifting from integration to independent living, and I believe we must pursue progress towards quality of life.

In the words of the Spanish poet Antonio Machado, “Wayfarer, there is no way; you create the way as you walk”. The HELIOS programme can map out the path towards independent living and quality of life, alongside the paths of other States, other cultures and other levels of development which can contribute to our progress and with which we can share our constructive experience as equals.

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social integration and independent living



the concept of independent living

Time and again I hear so-called experts in the rehabilitation field asserting that severely disabled people are not able to lead an independent life, that they are dependent on assistance and that self-determination is therefore impossible. I would like to demonstrate that, with the requisite funds and personal assistance, physical dependency can be overcome and independence achieved. Independence is a mindset, not a muscular function...

Self-determination as a social and political movement

In the late 1960s, people with a variety of disabilities got together in America to form a civil rights movement in order to protest against clinical living conditions in residential care, and in response to other disadvantages encountered in the education system, at work and in practically every sphere of their lives. The founders of this movement were people who needed a relatively high level of personal assistance in everyday life. Their key demands were the right to express their own needs, an independent way of life outside the confines of an institution, self-determination, control over assistance systems, assistance and involvement in decision-making on all issues relating to disability policy.

Adolf Ratzka (Sweden) put it even more clearly when, in a discussion of various forms of support, he stated that the aim of disability policy must be to give disabled people, individually and collectively, more social power. More power implies having adequate funds, defining social situations and setting the agenda. Funds should therefore be provided directly to the individual concerned, for example in the form of a personal budget as is the case in Sweden, Denmark and the Netherlands.

This is a new approach to disability. The independent living perspective postulates that, primarily, the problem of "disability" lies not with the person affected, but with the psychological and physical barriers society erects, and the often rigid support structures it sees as the answer.

It is also a philosophy of disabled people's needs. In this it differs fundamentally from the traditional philosophy of rehabilitation, which is therapy-orientated and essentially geared to the adjustment of disabled people to existing working and living structures. When this is successful, integration is said to have been achieved; otherwise, the individual is steered towards a rehabilitation "dead end". As Jeff Bernard (Austria) made clear in

his article "Kampf um Zeichen und Bedeutungen": "special institutions and special measures, of whatever kind, are not, contrary to the assertions of their proponents, the first step towards integration, but the very opposite. Only integration as such is integration; integration is therefore the negation of special institutions and methods."

Autonomy versus heteronomy

Every democratic society guarantees the individual the right to dignity and self-determination. The latter applies most importantly to accommodation, leisure, work and the choice of career, religion, sexuality and lifestyle in general. Disabled people who require a high level of care and assistance in their daily lives are often deprived of all those options except as regards their religion. On medical and financial grounds, medical officers, charitable organisations in charge of residential homes, and the welfare authorities all press for institutionalisation in cases where a high level of care and support is required. Do the nursing homes see each disabled individual with high assistance requirements as a new source of income? What is sure is that people in residential care lose the right to decide when they go to bed, get up, shower and perform various other intimate activities. Care plans regulate the daily routine, day in, day out. All-in nursing fees often go hand in hand with all-out arrogation of individual choice and control. Research in Sweden has revealed that there is no form of assistance provided in an institution that cannot equally be given in a family setting or in the person's own home.

The concept of independent living aims to restore to disabled people the control over their own body and lifestyle that other people take for granted. This implies that all the necessary assistance provided in an institutional setting can equally be given in the person's own home. The concept of independent living postu-





lates that the problem of care and support relates primarily to the rehabilitation authorities' response and provision rather than to the individual. Much of their care provision is a throwback to the hospital model of the early Middle Ages, treating disabled people as a homogeneous group.

Independent living also means living in one's own home – where we have control over who we see and how often. Only when we have the rights that go with living at home do we really have a say over our daily lives.

Independent living also means being in a position to make an absolute maximum of decisions for oneself.

Another factor in independent living is access to the information, advice and resources needed to determine how we live our lives. Independent advice must therefore be available, for example from other disabled people (peer counselling).

Disabled people as consumers of services

Much of the social service provision for disabled people has more to do with the way the professionals involved view disability and their support function than with the expectations of those directly concerned. We must do away with the paternalism in thought and deed which all too often casts disabled people in the role of victims and passive recipients of assistance, if they are to have any chance of self-determination and thus personal development outside the confines of institutional care. New support structures are required, where disabled people are no longer fobbed off with benefits in kind, but instead become consumers of services on the open market. They must accordingly be given the financial resources they need to gain access to various assistance services.

Personal assistance as the key to independent living

Adolf Ratzka states that personal assistance is one of the keys to an independent life and lifestyle. The assistance disabled people require is not fundamentally different from the help others need to develop and maintain their individual lifestyle.

Personal assistance gives disabled people access to outside support to compensate for things they find difficult or impossible in their daily lives. "Personal" implies that the assistance should be

geared to the needs and wishes of the disabled person. That way disabled people take their rightful place as the employers of personal assistants.

Those who cannot or do not wish to deal with everything themselves can also benefit from joining forces in cooperatives to organise assistance services.

Society's role in independent living for disabled people

All-in nursing fees agreed between financing bodies operating above local level and service providers regularly result in the all-out arrogation of disabled people's freedom of choice: the latter are institutionalised and given no control over the resources which are theirs by right. Disabled people are grouped together for treatment in accordance with the institution's own view of its function in the field of disability.

New thinking on care and assistance is urgently needed if disabled people are to enjoy a return to normal living conditions and self-determination in their daily lives.

Individual nursing fees tied to the person requiring assistance would be a step forward. Provision must be made for a non-means-tested personal budget paid directly to the disabled person, as exists in Denmark and has more recently been introduced in the Netherlands, the United Kingdom and Sweden. This is a prerequisite for self-determination, as it places those concerned in the position of consumers and of forces for change on the market for assistance services. As already mentioned, the establishment of assistance cooperatives helps all those who cannot or do not wish to organise things themselves.

Easy access to technical aids, without the need for senseless medical reports for example, is another way of promoting independent living.

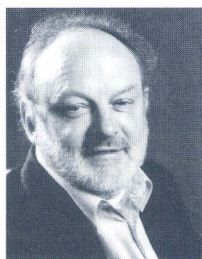
Recent announcements of new initiatives in Europe point to opportunities which could show the way forward for all the Member States of the European Union. Yet emancipatory options promoting independent living are often rejected on the grounds that they are alien to the national culture of the welfare system and cannot be imported – a handy excuse employed by hidebound bureaucrats. Good, practical solutions which promote self-determination and improve quality of life are always workable. An information policy drawing

quality of life

a European challenge

attention to good practice in the field of self-determination and integration for disabled people is needed to change attitudes and assist in the dissemination and implementation of practical solutions in many countries.

The exchange and information activities carried out under the European Union's HELIOS II programme enable examples of good practice to be collected and made available to a broad public. It can only be a matter of time before such measures are introduced in numerous countries – unless, of course, those who want to make money out of disabled people by setting up ever more residential homes win the day.



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For decades, doctors, planners, social workers and educators have determined “what is good” for people with disabilities. Whilst professional ideologies have moved from residential care towards community care and support, control has often remained with the professionals. What is needed is a meaningful dialogue with the persons concerned on what they consider to be their quality of life.

Why quality of life?

Quality of life is not necessarily a new concept but it is taking on increasing significance in the context of social and political developments in Europe. Action on social exclusion, participation and equal opportunities calls for debate about what the good life is, what determines the quality of life, and what conditions are necessary to enable people to follow their own convictions and shape their own lives.

This debate was initiated in Denmark by the Danish organisation for people with learning difficulties and recently presented at the first European conference on the quality of life for disabled people, which was held in København in December 1994. The conference was organised by the European Integration Network and the Social Development Centre with the support of the European Commission, through HELIOS II.

Researchers and practitioners from nine EU Member States discussed questions such as: how can we conceptualise the quality of life? Can it be measured? What are the potential benefits and dangers of developing quality of life as a social policy aim for the European Community? Can common concepts of European quality of life be defined?

Increasing awareness

Quality of life is not something a person simply has or receives. It is a process, not a state; something the individual actively works to create together with other people, as long as certain basic conditions are fulfilled. Living a “good life” means being able to determine the course of one's own life and having the opportunity to create an existence based on one's own dreams, visions, wishes and needs.

This heuristic definition has been central to the Danish debate on the quality of life. The key to understanding the conditions and opportunities necessary for a good quality of life is interpersonal relationships and day-to-day interactions with other people. What is needed is a definition not of a good quality of life but rather of the conditions necessary for people to make that life for themselves.

The prerequisites for quality of life can be discussed in relation to three basic categories:

The social network: the first condition is that relationships in the network should be marked by involvement, frequency, variation, balance and interaction over a period of time.

Mastery: the second condition is that the individual should have mastery over the social relationships he or she enters into, as this is an important factor in the mastery of one's own life.

The self: the third condition is that these relationships should result in a positive experience of the self, of one's importance to others.

We can use the idea of quality of life first of all to consider the circumstances which enhance people's opportunities to actively create quality of life for themselves. Secondly, we can attempt to bring about the necessary dialogue with the individuals concerned on their complaints and wishes, dreams and ideas regarding their everyday lives. Within the context of this dialogue we can contribute to the development of their living conditions.

Quality of life is both subjective and objective. It is therefore impossible to disregard the objective aspect of a person's situation; living conditions have to be included. Without an objective frame of reference, it is difficult to take a critical attitude to statements such as: "I am happy, because someone like me does not deserve better", or: "I have a good life, because I get three square meals a day and the staff are very kind".

As such, the concept of quality of life is designed more to stimulate awareness than as an operational definition.

Measuring quality of life

There are, however, serious issues involved, concerning the way the idea of quality of life is used in various contexts today. Firstly, the idea that the term can be interpreted to the extent that quality of life becomes the object of measurement

against predetermined "objective" parameters is problematic. Phenomena such as happiness, love, joy and quality of life cannot be measured in any meaningful way. Furthermore it is unacceptable to use such measurements (quality of life coefficients) in relation to difficult ethical choices, e.g. prioritising within the health sector: which life warrants the investment of scarce resources.

A dialogue between concept and practice

Denmark works on the basis of a strategy of change, as expressed in the term development project, in which research and the process of change feed into one another. The researcher collects data from the processes of change which have been set in motion and participates actively in the evaluation procedures – with the purpose of adjusting, developing and consolidating objectives at regular intervals.

Change is therefore initiated and new approaches tried out not primarily on the basis of written reports or research, but within a framework which involves all the various groups (disabled people, social pedagogues, social workers and researchers) in the process of change. This approach is founded on the desire to change specific aspects of everyday practice.

A development project based on experience and democratic participation can work only within the context of a dialogue between disabled people and support personnel, in which all participate with equal weight and worth, on the basis of a common desire to change something in the everyday life they share. The dialogue itself involves changes in self-knowledge and scope for action for all concerned. By tak-

ing part in the project on an equal footing with others, disabled people develop such qualities as readiness to act, awareness of choice and an increased sense of mastery – because their aspirations and visions can be put into practice (or, if not, one at least knows why not).

A European dialogue – the way forward

In the consensus which emerged at the conference in Denmark, the emphasis was on establishing conditions and contexts in which disabled people and support services can enter into meaningful dialogue. A move towards enabling and empowering disabled people to have a say over what counts as quality in their own lives. The use of the term "development projects" indicates that the quality of life is a dynamic concept and may change in response to personal development and different contexts.

The conference recommended the establishment of a European network on the quality of life for disabled people, to focus on exchanges of experience and results from research and development projects in the Member States, stressing the true involvement of disabled people themselves. This will include a broader process of dissemination of and dialogue on innovations achieved by the joint efforts of researchers, disabled people, support staff, social workers, etc. in and among the Member States.

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personal assistance

The Assistenzgenossenschaft
Bremen – a personal
assistance services (PAS)
cooperative in the city
of Bremen, Germany –
uses the term “assistance”
– or, more correctly, personal
assistance – for every kind of
personal help that enables
somebody who is in need
of assistance to lead an
independent, self-determined
life in the community.

Personal assistance is geared to the PAS user's needs. By consistently using the terms “assistance”, “assistance user” and “assistant”, we aim to change the language used in reference to disabled people and attitudes towards them. Usually terms like “care” and “help” are used, and “carers” and “helpers”, thus turning the assistants into Good Samaritans and disabled people into passive recipients of charity, whereas somebody who uses personal assistance services is active and in charge of his/her life.

In our opinion, four rights are crucial to an independent life with personal assistance: the right to choose who provides assistance, the right to decide when and where assistance is provided, the right to instruct the assistants oneself and the right to control the money spent on assistance.

Having set up our Centre for Independent Living in 1986, we soon realised how inadequate mobile service provision was in Bremen. The main criticism was that decisions were – and still are – made on the basis not of the PAS user's needs and wishes, but of those of the organisation.

So how could personal assistance be organised in such a way that the consumers have full control and can bring all their rights to bear? One option is for disabled people themselves to employ their assistants. But it is not the right solution for everyone: some cannot and others do not want to operate in that way.

What was needed was a compromise: maximum consumer control, but without the burdens that being an employer entails. In our search for a solution we came across the cooperative model, which is run on very democratic lines, thus enabling PAS users to monitor the work of their service provider and actively share in the decisions being made.

The cooperative acts as a kind of mediator between PAS users and assistants in the best interests of the former – after all, the service grew out of the independent living movement. It has contractual arrangements with both parties: assistance contracts with the PAS users, setting out the number of hours of assistance required, and employment contracts with the assistants. The latter are not generally required to possess specific qualifications; the most important criterion for employment is whether the PAS user wants to work with a particular person.

The Bremen cooperative was set up in 1990. Today it arranges assistance for 37 people with a variety of physical and mental disabilities. Unfortunately, a new law on the financing of care and assistance entered into force on 1 April which will water down the individual's existing legal entitlement to appropriate help. The impact of the new care insurance law could be to put our philosophy of self-determination in jeopardy and hand control over to the care insurance funds. No one yet knows what the situation will be in the future, but we will take political and practical action to ensure that we can maintain our present standards of personal assistance.

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peer counselling

from wish to reality

Peer counselling is the first method to offer a structure in which optimum benefit can be gained from the practical experience of disabled people. Originally from the US and now practised in a number of European countries (including the Netherlands, Germany and Sweden), peer counselling is seen by the HELIOS programme and the international independent living movement as a major and innovative contribution to securing the greatest possible independence for disabled people.

Why peer counselling?

Like anyone else, disabled people have wishes regarding the kind of life they want to lead. Putting those wishes into practice – or trying to – brings them up against obstacles. Both in the outside world (inaccessibility, lack of facilities, preconceptions, etc.) and in their own, private world (a negative self-image, fears and uncertainties), a great many things can stand between them and their goals – and can sometimes sap their determination to succeed.

The realisation that you are not the only one with problems nor alone in being barred from full participation in society can be a considerable mental boost in itself. Another important factor is the awareness that the difficulties faced by disabled people are not simply a personal problem, but also a socio-political issue.

But peer counselling is not about “crying on each other’s shoulder”. Quite the reverse in fact. The underlying principle is that disabled people can learn from one another’s experiences, inspire one another, and support one another in their efforts to achieve optimal independence.

The method

The role of the peer counsellor is different from that of the average professional assistance provider in that he or she is also disabled, and thus very much a member of the group. Peer counsellors also function as a role model; they are people who have found their place in society and who are in a position to stand back and take an objec-

tive look at their own experience. It is also essential for the peer counsellor to have a salaried position, thus confirming the social importance of practical experience.

The whole peer counselling process revolves around the wishes and ambitions of the individual concerned. Guided by the peer counsellor and by means of a step-by-step approach, exercises, role plays, feedback from peers and the pooling of practical experience, each makes constructive efforts to achieve these aims. There are no preconceptions as to what is or is not possible: individual strengths and creativity are developed by making the most of every available possibility. The basis for the whole process remains the personal responsibility of the disabled person. Peer counselling is usually a group activity. Regular meetings are held, with the possibility that after a certain period of time the group will continue on their own, without a peer counsellor. A peer counselling group may be formed to tackle a particular subject such as housing, work or personal relationships, or start out from the general question of “what do you want to do with your life?”

In practice

Experience of peer counselling in Europe to date confirms its value and effectiveness. As the circumstances of disabled people vary from one country to another, the method is adapted to requirements at local level. In Scandinavia and Germany, for example, peer counselling is usually linked to centres for personal assis-

tance/independent living set up by disabled people. In the Netherlands, the preference is for cooperation with organisations and institutions (schools, local government, etc.) on a particular topic. This ensures that peer counselling remains as far as possible directly relevant to the everyday experience of those concerned.

The latest development is the use of peer counselling as an instrument in clarifying requests for assistance. By assisting peers (including on an individual basis) in coming to an understanding of their own situation and needs, assistance provision can be geared towards consumer demand instead of supply.

What can peer counselling mean for a disabled person? One participant summed it up as follows: “a salutary kick in the pants just when I needed it.”

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towards self-determination

“I know what I want!
– People with learning
difficulties moving towards
more self-determination”
was the slogan for last year’s
conference of the Bundesve-
reinigung Lebenshilfe für
geistig Behinderte in
Duisburg (Germany),
which was supported by
the European Commission.

The “Duisburg Declaration” drafted by the programming committee of disabled people called, inter alia, for freedom of choice regarding education, living arrangements, work and leisure, more participation in decision-making in sheltered workshops, and proper employment contracts. The declaration also proposed forming “groups where we can talk to one another”. Developments in the Netherlands, Sweden and the United Kingdom are seen as models on the way towards self-determination for people with learning difficulties.

The need to exert maximum influence over one’s daily life is fundamental to human nature. When a person is heavily de-

pendent on outside assistance, however, it is sometimes difficult to see where independent action and decision-making can begin. The lives of many people with learning difficulties are still governed by other people’s decisions. The fundamental choices expressed by people with severe and multiple disabilities are still all too often ignored. And less severely disabled people too are deprived of the opportunity to decide for themselves on many issues – from the choice of job and where they want to live to moving in with a partner. The Duisburg Declaration aims to give the impetus for trying out new forms of participation and self-determination for people with learning difficulties.

the Duisburg Declaration

We want more control over our own lives. For that we need other people. But we do not want simply to tell others what to do – we can take action ourselves.

- We want to take on more responsibility. (E.g. a prompt start in the workshop after the break.)
- We want to take care of those weaker than ourselves. Severely disabled people can also express what they want. It may not take the form of speech, but it shows in their face and behaviour.
- No one should be discriminated against on the grounds of disability. (E.g. a family with a disabled child should be able to rent a flat just like anyone else.)
- Everyone has a right to take part in the life of society. (E.g. no one should have to live like a prisoner in a psychiatric hospital; that is no place to live.)
- Everyone has a right to be treated as a human being. (E.g. it is unacceptable for disabled people to be fed as if they were babies or told when to go to bed or to the toilet.)
- When politicians speak of self-determination, they should not see it as a cost-cutting measure. Self-determination does not mean life without assistance. Self-determination is making one’s own choices and decisions.
- We wish to choose which school we attend: a mainstream school with non-disabled people or a school for people with learning difficulties.
- We wish to choose where and how we live our lives: with our parents, with a partner or with friends, in a hostel, in independent groups or in shared accommodation. Sheltered housing should also be available.
- We would like more participation in decisions at work, whether in sheltered workshops or in companies of other kinds. We want proper employment contracts.
- We would like to earn a living wage.
- We want to be part of things. We want to play sports, go to the pub, go on holiday, etc. like everyone else. We would like to make our own decisions about friendships and personal relationships. It should be easier for us to meet and indeed live together. Everyone learns best from personal experience.
- Parents are often too well-meaning. They do not let us try things for ourselves. There is nothing dreadful about making mistakes and trying again.
- Carers should help us do things by ourselves. They should be tolerant towards disabled people. We want to work with them; we are not there to take orders. How can we gather strength?
- We can do more than we are given the chance to, for example going out alone or taking the train. We want to make that clear, even if it sometimes involves opposing the wishes of parents or carers.
- We want regular contact with disabled people from other places, to find out how they live. That way we can compare and see where improvements could be made. We want to form groups where we can talk to one another.



sport and tourism

In ancient times, the people of Rome demanded bread and the entertainment of the arena. Our recreational needs take a somewhat different form today – but they are no less important. Every individual, disabled people just the same as anyone else, claims the right to culture, entertainment, physical exercise and travel. In short, the right to make the most of their free time.

Sport and tourism, to take just two of these activities, present unique opportunities for getting away, making discoveries and meeting new people.

European integration, which is playing an ever more tangible part in our daily lives, can open up new choices for disabled people in both areas.

Did you say Eurohandisport?

With the development of major events such as the Paralympic Games, sport has become a vehicle for a new, positive image of disabled people. Media broadcasts of the top-level sporting achievements of disabled athletes have made an impression on a broad public.

The European Union accordingly decided a few years ago to make its contribution to sport for disabled people, both in the competitive field and as a recreational and/or therapeutic activity. The watchwords are coordination, and support for European projects.

In the interests of coordination, the Commission has encouraged the development of national committees on sports for disabled people, composed of federations addressing various types of disability, and also promoted the establishment of the European Committee on Sports for People with Disabilities in November 1993.

The European committee, chaired by Dr Price (United Kingdom), meets twice a year on the initiative of the European Commission (DG V, Integration of disabled peo-

ple division, and DG X, Sports sector). Its main aims are to encourage disabled people's participation in sporting activities, promote information exchange and advise the Commission on its initiatives in this field.

The Commission supports projects with a European dimension – both major, high-profile events such as the Paralympic Games (Barcelona, Tignes, and Madrid in 1992) and Special Olympics Europe, and less widely publicised competitions and championships which nonetheless draw hundreds of athletes and spectators every time.

One of the criteria for grants is whether a project is innovative and likely to promote participation in new forms of sporting activity. New technologies in particular open up new prospects for the most severely disabled people.

The Commission is due to provide support for more than 50 projects in 1995, acting on the opinion of the European Committee on Sports for People with Disabilities.

Proof, were it needed, of the value of European initiatives in this field was recently furnished by the three new Member States of the European Union – Austria, Finland and Sweden – at the International Winter Games in Solleftea (Sweden), when they expressed their eagerness to engage in cooperation as members of the European committee and begin submitting projects to the Commission.

Tourists against the odds

Even more than sport, which is a matter of taste, travel is a leisure activity which enjoys almost universal popularity. Disabled people, so often limited in their mobility by a hostile environment, want to share in the joys of discovery that travel has to offer. But what they do not want is an obstacle course.

Despite variations from one country to another in terms of access to tourist infrastructure, the tourist industry in Europe clearly still has a long way to go before it can claim to be open to everyone.

What is needed to help improve the situation is debate between the various parties at European level. To this end, the relevant Commission departments – DG V and DG XXIII (Tourism unit) – have worked together to orchestrate the establishment of a working group under the HELIOS programme, to complement the Community action plan for tourism adopted by the Council following the European Year of Tourism (1990).

The Independent Living, Tourism for All group comprises three experts from each Member State of the European Union, representing associations of people with physical and mental disabilities on the one hand and the tourist industry on the other. It promotes exchanges of experience and advises the Commission on establishing a policy on accessible tourism.

The work of the European group is relayed within the Member States by national coordination units set up on the initiative of and with cofinancing from the Commission.

Its activities to date include preparing two guides, one for disabled tourists (*Accessible Europe – A Guidebook for Disabled Tourists*), the other for professionals in the tourist industry (*Handbook for Tourism Practitioners – Making Europe More Accessible to Disabled Tourists*). Following an invitation to tender, the NGO Mobility International produced the guides, which are due out this year.

Other projects, such as “Euro Cities through Touch” for blind tourists and the ITAC conference on training in Toulon, have received Commission backing. The Independent Living Group has chosen as

for all



its priority themes for 1995 accessibility, a discussion of norms and signs, information and training. Highly practical recommendations suitable for use by the tourist industry will be developed and given broad dissemination.

In all its work, the group cooperates and consults with the partners directly concerned. Feedback on the methods used and the initial results of action taken so far has been extremely encouraging.

Xavier Coyer

Expert with the European Commission

**For further information,
please contact:**

- Mobility International,
rue de Manchester 25, B-1070 Bruxelles.
- European Commission,
DG V/E/3, Integration of
disabled people division,
DG X (Sports sector),
DG XXIII (Tourism unit),
rue de la Loi 200, B-1049 Bruxelles.



In their bid for independence, Roland Roux believes, disabled people should be involved in the establishment and control of the services they require, so as to ensure the development of solutions which will address their specific aspirations.



practising independence every day

20 years ago, I lost my sight in a hunting accident. In a split second my life was turned upside down. I first had to cope with the physical pain, then the emotional suffering caused by my changed perception of the world around me. Even familiar surroundings now seemed hostile. I felt helpless, my wife and children too. Other blind people gave me practical advice, but I did not really begin to regain independence until I went on a three-month rehabilitation course at a specialist centre.

Gradually I learned to change the way I lived, to overcome my disability and develop the senses that remained to me – particularly hearing, touch and smell – and also my memory. Moving around outside – in town, on public transport, at all times and in all places –, sweeping the ground with a long stick; serving oneself

at table; eating tidily; being independent in one's daily life; communicating in Braille – all these things demand very specific skills which only specialised trainers can teach. But I have never allowed and will never allow other people to make my decisions for me. Teachers, skills and equipment cannot replace taking responsibility for one's own life. Rehabilitation also takes willpower and perseverance. Independent living is a daily effort.

As there were, at local level, no organisations providing services suited to our needs, four of us, all with physical or sensorial disabilities, set up our own association to help disabled people to take control, learn to enjoy life again and move towards maximum independence. Our group is the GIHP (Groupement pour l'insertion des handicapés physiques – group

for the integration of physically disabled people) Aquitaine, a regional branch of the French national GIHP. One of our innovations was the development of a transport-on-demand service for disabled people, which was unheard of at the time. At last, this offered an opportunity to go out as and when we pleased: to work, school, university, places of worship and elsewhere. And what started off as a small-scale local initiative eventually snowballed into a partnership with other associations in the region. Our Trans'Adapt transport system was given the status of a public service after a few years, and is now government-financed. Another early project was setting up a multidisciplinary team to assist disabled people with the transition from residential care to an independent life at home. We work with reha-

In 1985, the association of disabled people GIHP Aquitaine set up a multidisciplinary team to promote the transition from residential care to independent living.

Preparation for leaving the institution and returning to one's family and social environment is essential. Some people may be hospitalised for months. Their discharge from the institution is a time of reappraisal, when they take stock of their recent disablement and the changes it implies.

The multidisciplinary team offers support over a limited period, to help each individual gain self-knowledge and self-acceptance, and thereby self-confidence. The basis for the support is a coaching contract, which sets out the goals the per-

son wishes to achieve with the team's assistance, and the total duration of the process; thus the disabled person is the architect of his or her own development and retains freedom of choice.

The support we provide may take one of three forms:

- . psychological support in developing a strategy for leaving the centre and realistic plans for a new life;
- . occupational support (occupational therapy): making practical preparations for the transition (equipping the home, making provision for access, investigating the adaptations and technical aids required, etc.); mastering new actions and approaches which will be necessary for performing daily tasks;

. social and educational support, preparing the person to cope with new difficulties (financial, administrative, etc.) and reorganise their life (arrangements for errands, home assistants, etc.).

GIHP Aquitaine offers two forms of assistance in particular:

1. Temporary support services: the group runs halfway houses for people in transition between a sheltered environment (rehabilitation centre, hostel or family) and a mainstream living environment. Flats are available for a limited period of between three and six months, to enable the people concerned to develop practical arrangements they can use if they then decide to live on their own.

2. Home support services: these are domiciliary services for people who do not want to make the transition via a halfway house, but wish to return directly to their own homes.

Christine Loubière
Psychologist

son wishes to achieve with the team's assistance, and the total duration of the process; thus the disabled person is the architect of his or her own development and retains freedom of choice.

rehabilitation professionals from a wide range of disciplines: psychologists, occupational therapists, physiotherapists specialising in the treatment of psychomotor disorders, social workers and others. The service is financed by local government and the social security authorities. It endeavours to teach the skills necessary for independent living, while respecting freedom of choice, and seeks to develop the individual's capacity for self-determination. But we, as disabled people, are the real experts when it comes to gearing service provision to our requirements.

If the demands and fundamental needs of disabled people are to rely on public initiative alone, many may remain unaddressed. I believe disabled people themselves share in the responsibility for initiating the projects which will meet

their needs. But for those projects to survive and thrive, new alliances must be forged between local administrations and professionals in the social field. My own experience indicates that this new partnership can have a real influence on society, increasing awareness of people's interests. And it should be noted that this change of attitude does not necessarily require more staff or more funds, simply a shift in ways of working and thinking.

Roland Roux
Chair of GIHP Aquitaine
Vice-Chair of the Groupement
français des personnes handicapées
Résidence Mozart
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handynet

users first



Readers will hardly need reminding that the European computerised information system HANDYNET implemented under the HELIOS programme comprises on the one hand a multilingual data base on technical aids, their manufacturers and retailers and the national statutory procedures enabling disabled people to obtain them and, on the other, an electronic journal and E-mail system.

In 1994, the European Commission submitted to the Council, the European Parliament and the Economic and Social Committee a report on the HANDYNET system and its evaluation by people who had an interest in the information (including many disabled people) but were not involved in data collection or the development of the HANDYNET network in the various Member States.

On 6 December 1994, the Council, on a proposal by the Commission, formally opted for the continued development of the HANDYNET system – although not its extension to new modules – up to 31 December 1996 (the end of the HELIOS II programme).

HANDYNET – on the market

The European Commission subsequently submitted a distribution strategy for the HANDYNET data base on CD-ROM to the advisory bodies, further to the suggestions Parliament had made in its opinion. The Commission proposal took due account of the interests of both disabled people and the HANDYNET national coordination and collection centres, and complied with the principle of subsidiarity.

The Commission proposed on the one hand distributing a number of free copies of the CD-ROM via the HANDYNET national coordination centres to organisations designated by each Member State, and on the other selling copies of the HANDYNET CD-ROM to any interested party both inside and outside Europe.

Member State representatives on the HELIOS Advisory Committee were therefore invited to indicate to the Commission the number of free copies they required, up to a maximum quota based on the number of MEPs representing their Member State.

At the same time, a call for tenders was published in the Official Journal of the European Communities of 16 March 1995, inviting interested organisations to apply for tender specifications regarding the production, marketing and distribution of the HANDYNET CD-ROM from issue No. 9, which is due out in June 1995.

By 31 March 1995, the deadline for the submission of bids, no fewer than 120 tender information packs had been sent out.



It is worth mentioning the breakdown of the response by Member State:

Austria	1
Belgium	30
Denmark	0
Finland	0
France	11
Germany	19
Greece	3
Ireland	3
Italy	13
Luxembourg	1
Netherlands	5
Portugal	0
Spain	8
Sweden	1
United Kingdom	25

The bids were examined on 19 April 1995.

The designated organisation took part with the HELIOS Team of Experts in the preparation of CD-ROM No. 9 (June 1995), in order to familiarise itself with the tools and know-how developed to date. It should be in a position to work independently on the production of issue No. 10, scheduled for the end of 1995.

Preliminary estimates indicate that at least 2,000 copies of the CD-ROM should be financed by the Commission for distribution free of charge in the Member States, and a further 2,000 copies will go on sale.

After consulting the organisation responsible for production, marketing and distribution, the HANDYNET national coordination centres and the members of the HELIOS Advisory Committee, the Commission set a single sales price for the CD-ROM information tool.

It is to be sold by subscription (three issues a year).

The electronic journal and E-mail system

With information superhighways very much in the news, finance from the IDA programme and cooperation between HELIOS/HANDYNET and the EURES programme have paved the way for an extension of the HANDYNET E-mail system, hitherto reserved for the HANDYNET national coordination centres.



The installation of workstations will be free of charge and is planned in two stages:

- from May to June 1995

HANDYNET national coordination centres
18 workstations
HELIOS Advisory Committee
29 workstations
European Disability Forum
33 workstations

- from June to October 1995

HANDYNET data collection centres
60 workstations
Members of the HELIOS working groups
93 workstations

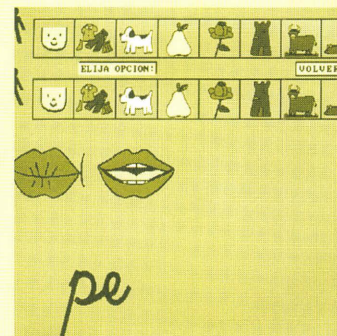
to which should be added the workstations of the Commission (DG V/E/3) and the HELIOS Team of Experts.

Energy, synergy

Synergy requires information and communication. With this in mind, a training session was due to be held in Belluno (Italy) from 28 June to 1 July 1995, as part of a drive for increased synergy between the HANDYNET national coordination centres and the non-governmental organisations within the European Disability Forum. The event was to focus largely on the use of the HANDYNET data base and the E-mail system.

We can be confident that the session will have revealed new areas of possible cooperation between professionals and users and have developed communication and information exchange to the benefit of equal opportunities.

Josyane Pierre
HANDYNET Coordinator
HELIOS Team of Experts



equality and the social integration of people with

Efforts to achieve equality between disabled and non-disabled people are unlikely to be successful as long as there prevails widespread conceptual confusion about the meaning of the term equality. Aart Hendriks argues that the promotion of equality does not necessarily mean that disabled and non-disabled people should always be treated identically. He concludes that social integration policies exclusively targeting disabled people and not challenging their physical, attitudinal and legal environment are highly discriminatory and doomed to failure.

In response to the atrocities of the second world war, powerful mechanisms were created to ensure the protection and promotion of human rights. That war once again demonstrated that “different” people, including people with “different” abilities, are constantly at risk of becoming the scapegoats of intolerant political ideologies. After the war, the obligation to respect and protect human diversity was globally acknowledged as a fundamental human value. The concept of respect for human differences is reflected in the principle of equality, a principle that figures prominently in all major human rights instruments. According to the 1948 Universal Declaration of Human Rights, for example, “all human beings are born free and equal in dignity and rights”. Other international human rights treaties, as well as many national laws, contain similar provisions.

None of the international treaties, nor any of the national laws, contains a clear definition of the term equality. This may explain why people attach such a range of meanings to the concept. There seems to be substantial support for the view that the principle of equality seeks to promote sameness by requiring all people to be treated identically; failure to do so thus constitutes “discrimination”.

Confusion about the meaning of equality can be illustrated by looking at the history of some established equal rights groups. In many countries, women’s rights, racial equality and gay rights pressure groups started off by demanding

the same treatment as those “others” – usually white, heterosexual males – they took as their yardstick. Their equal rights campaigns were frequently successful; in numerous countries anti-discrimination laws were adopted or expanded prohibiting all kinds of distinct treatment. Soon, however, it was realised that laws and policies promoting identical treatment failed to rectify existing inequalities. It was also felt that genuine equality could not be achieved by promoting identical treatment, since it was still tacitly expected that “different” people should one-sidedly adapt to the norms and standards of “other” people. Instead of challenging the existing power structure, these laws and policies merely institutionalised structural inequalities in society. So equal rights movements began advocating respect for individual and group diversity and demanding similar treatment in situations where people are in a similar position and different treatment in situations where this may be necessary to cater for different needs.

This evolutionary process seems to be directly inspired by the thoughts of the Greek philosopher Aristotle. More than three hundred years B.C., Aristotle said that “Equality in morals means this: those things that are alike should be treated alike, while things that are unlike should be treated unlike in proportion to their unlikeness.” It took the above liberation groups many years – and painful disillusionment on numerous occasions –

“different” abilities

to appreciate the second part of Aristotle's visionary teaching. It is to be hoped that politicians, policy-makers, the international disability movement and all others involved with the promotion of equality between disabled and non-disabled people will not make the same mistakes. After examining the content and scope of some of the current social integration programmes there are, however, grounds for concern. In many places, “social integration policies” seems to be a euphemism for forcing disabled people to adapt to the norm and standards of the self-proclaimed “mainstream”. This runs counter to the very meaning and intentions of the principle of equality as described above. Genuine equality implies that both parties, disabled people and their non-disabled peers alike, make efforts to bridge the gap that keeps them apart. This would imply that social integration policies should not merely be a set of measures aimed at facilitating access to “mainstream” society, but should also embrace measures aimed at breaking down the physical, attitudinal and legal barriers that effectively prevent participation in society. To give an example, policies seeking to guarantee disabled people access to public transport should require public transport companies not only to assist people with motor disabilities to gain access to their services, but to make transport accessible to the greatest possible number of people of all groups. This is not only in accordance with the aspira-

tions enshrined in the principle of equality, but also prevents disabled people from becoming unnecessarily dependent on the generous and charitable help of others. Achieving genuine equality would imply a redistribution of resources and entitlements commensurate with varying individual needs. Social integration should therefore be geared to enhancing independence and redressing structural inequalities. Social integration policies that expect disabled people to shoulder the burden of their “difference” all by themselves may not only exacerbate inequalities – they are also highly discriminatory and doomed to failure.

Aart Hendriks

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NGO definitions

It seems that a linguistic inflation of the term "Independent Living" (IL) has occurred – without, however, a corresponding increase in real independence for disabled people. It is time to look again at what Independent Living means, in order to prevent a misuse of the term by people trying to disguise charitable dependence as something else.

The IL movement has its own history and agreed definitions of Independent Living. To quote Adolf Ratzka (ENIL conference, Sweden, 1991):

"The IL [movement] sees disablement as a social and a political problem. It follows the example of the issues and strategies of the black civil rights movement and of the feminist movement. The main issues are the articulation of one's own needs, self-determination, the consumer-orientation of assistance and participation on a political level and in administration."

A brief overview of a number of European NGOs' definitions of Independent

Living reveals that nuances alter depending on the particular constituency and disability represented by the NGO, but, significantly, they do not alter in substance. To cite but a few examples:

"IL is a process of consciousness raising and empowerment. This process enables disabled people of all ages and with all types of disabilities to achieve equalisation of opportunities and full participation in all aspects of society.

"Disabled people must be in control of this process. Meaningful choices must be available in order to exercise control." (Disabled Peoples' International)

"Giving people equality of opportunity, autonomy to determine lifestyle, removal of barriers to choice, information and mobility and the opportunity for full social integration." (European Blind Union)

"The term 'Independent Living' implies that people with mental health problems reside in ordinary houses... where they can... have an influence on their environment, within the normal limits of society, choose their own lifestyle and make decisions, be fully participating members of their local community... work or purposeful daytime activity, followed by evening and weekend recreation." (European Re-

Opinion

definition of "disabled person"

According to DPI-European Union Committee, it is wrong to define disability as a "problem" of the individual (cf. HELIOSCOPE No. 2, "Human Rights for the 1994 European Day"). Instead, "Disability arises from interaction of the impairment, condition of functional limitation, with a society which produces barriers to integration and understanding." The traditional WHO classification (1980) differentiates between impairment, disability and handicap. We do not see DPI's point in dropping the concept of "handicap" to replace it with "disability" – and in turn replace "disability" with "condition of functional limitation". This is, as we understand it, the consequence of DPI's line of argument.

Webster's dictionary defines "ability" as "competence in doing, skill". The prefix

"dis-" suggests "being apart from", i.e. not having – or having reduced – ability. If we speak of a person as having a disability, we suggest that he or she deviates from the "normal" frame of ableness, whether physical or mental.

We think that there is a danger of confusion in adopting the change in terminology proposed by DPI. The strength of the WHO's proposal lies in its demarcation of effects on the organic, human and social levels. It suggests ways of dealing with the difficulties experienced by disabled people on these three levels – medical, rehabilitation and political. Of course, we agree that the WHO definition depends too much on the health concept. However, interesting work is being undertaken in this area, for example by Fougeyrollas in Canada. Also, why drop a

classification we have fought so hard for? Let us concentrate on further developing the classification proposed by the WHO, and not embroil ourselves in the futile struggle of renaming established concepts – particularly if the new term is based upon a questionable way of thinking.

Bertil Sköld

Department Director

Swedish Association of the Visually Impaired

of Independent Living

gional Council-World Federation of Mental Health)

“Independent Living for deaf people means living without communication barriers. This should be reached by facilities like sign language interpreters, subtitling on television, text telephone and relay services.” (European Union of the Deaf)

“People with disabilities dependent on continuous assistance independently of decisions made by others wish to live their lives outside the institutions. They need adapted housing, transport to leisure activities, services including personal assistance as well as adequate financial means.” (Fédération internationale des mutilés, des invalides du travail et des invalides civils)

“Living conditions offered to mentally handicapped people should always compare favourably with those of the community in which they live... they should...

take part in all decisions which affect the quality of their lives and the services they need.” (International League of Societies for Persons with Mental Handicap)

“[To] enable and to empower disabled people to live the lives of their choice, with appropriate support to allow full social integration.” (Mobility International) Within the concepts of Independent Living put forward by the NGOs, brevity had to prevail. It is important to note that the same key elements recur: autonomy, choice, integration, equality of opportunity, empowerment and control. 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 through the advice of other people with disabilities, otherwise known as peer counselling.

We should remember that “independence” in itself does not guarantee happiness or quality of life. All human beings, regardless of ability, tend to need each other and need to be needed; independence without the chance of normal friendship is the same as social isolation.

It would be simplistic to conclude that everyone agrees on the goals and how they should be achieved. Real independence is probably within reach of few at this very moment – an elite notion. Many people are still living in institutions or at home against their will in Europe today. Political struggles over the next few years need to take into account the broad lines of agreement across disability groups and national borders, and not leave anyone behind.

Jackie West
Mobility International

The article in HELIOSCOPE No. 2 was not a reprint of the report of the proceedings of the plenary meeting held in October 1994, but a briefing paper distributed prior to the meeting. The paper was agreed by the working group of the European Disability Forum, and was intended to stimulate discussions – not to put forward the views of any one organisation. The article certainly should not have had DPI-EUC's name attached.

At the plenary meeting, participants did not come to a definitive decision concerning a definition of disability. The agreement was in relation to the context in which disability should be defined – that is, the “social context” which is supported by the World Programme of Action and the UN Standard Rules. Also, the use of the word “handicap” and “disability” were not discussed – partly because for many people at the meeting the two words are the same.

For instance, in French there is no other word for “disabled” except “handicapé”. However, this is an important discussion point, which was highlighted by the Special Rapporteur who prepared the final report on Human Rights and Disability for the United Nations Human Rights Commission. We are increasingly finding that discussions on this issue at a world level are difficult: when one language uses one word, it is translated differently in another language – and unless both speakers are fluent in the other's language, nobody realises the difference.

The participants in the meeting recognised that there have been problems with the WHO classification, partly because it has come from a health and impairment perspective. Since WHO adopted and published the ICIDH in 1976, the organisation has been encouraged to revise the classification, and particularly to incorporate so-

cial and environmental factors. The revision has not yet materialised, and the plenary meeting expressed the need for representatives of disabled people's organisations to be included in future discussions on this matter. Disabled people were not involved in agreeing the original ICIDH definition. We have been seeking an alternative definition ever since – and the work of Patrick Fougeyrollas could be helpful. But we must understand each other and understand the context in which we are speaking.

Rachel Hurst
Chair of DPI-European Union Committee

synergy

the European Disability Forum and the Commission

In recent years, organisations representing disabled people have been strengthened by various Community programmes and actions in which they have identified themselves as key stakeholders.

One tangible result of this is the development of the European Disability Forum as the voice of disabled people at European level, set up in the framework of HELIOS II. Because of its representativeness and its competence – covering the whole spectrum of disability throughout the Union – the Forum is gaining credibility and recognition at all levels within the Commission and the other Community institutions. And as such, it is a major component in creating an infrastructure in which “synergy” can take place, ensuring first and foremost consultation with consumer organisations. This spirit of cooperation at policy level will have positive repercussions on the practical implementation of Union programmes and initiatives at project or grass-roots level. This is a notion which is inherent within both the White Paper on European Social Policy and the White Paper “Growth, Competitiveness, Employment”, and must be developed.

Specifically, the White Paper on Social Policy states that “the Commission will build on the positive experience of the European Disability Forum to ensure that the needs of disabled people are taken into account in relevant legislation, programmes and initiatives.”

We are in an era when we can ill afford divergence of efforts and approaches. If the concept of synergy is not seen as an integral aspect of our work at all levels we run the risk of endorsing an ad hoc, piecemeal approach which will have minimal or even a negative impact on the lives of disabled people.

A powerful demonstration of “synergy” is a joint initiative by the European Disability Forum and organisations representing older people, and Directorate-General V responsible for social affairs and Directorate-General XIII responsible for RTD within the European Commission, to explore in further depth the role

which research and development can play in improving our quality of life as we approach the millennium. Such discussions will shape a comprehensive research programme in the future in which all partners are actively involved, and will ensure that developments in new technology respond effectively to the needs of the end user.

A prerequisite for “synergy” is effective, on-going communication and information exchange. The setting-up of the electronic mail system for HELIOS partners in cooperation with the Commission project EURES, in itself an example of synergy, will assist in responding to the information needs of the European Disability Forum members.

Johan Weseman
*Chair of the European
Disability Forum*

Directorate-General V's Integration of disabled people division: main bilateral cooperation activities

- DG I: development of programmes to assist disabled people in central and eastern European countries (PHARE and LIEN programmes and RI-ECA study)
- DG III: inter-DG consultations on motor vehicles (buses and coaches) and lifts.

Motor Vehicles Working Group and HELIOS Mobility and Transport Group.

- DG VII: Transport – HELIOS Independent Living, Mobility and Transport Group. Contribution to the action programme for transport for people with reduced mobility and to COST project 322 (low-floor buses).
- DG X: sport for disabled people. Co-leaders: DG V and DG X. Regular meetings between the two directorates-general. Working group and

European Committee on Sports for People with Disabilities. Support for projects for European sporting events.

- DG XIII (besides the cooperation mentioned in our article): cooperation in the field of telecommunications (accessibility of terminals).
- DG XXII: education and training programmes, in particular SOCRATES and LEONARDO. Regular meetings between the two directorates-general and the HELIOS Integrated Education Group (involvement

of DG XXII). Measures to ensure access to all the programmes of DG XXII for disabled young people.

- DG XXIII: tourism for all. Regular meetings between the two departments. HELIOS Independent Living, Tourism for Disabled People Group. Support for projects.

All Party

Disablement Group

under way
for the intergovernmental conference

The European Parliament Disability Intergroup's highest priority in 1995 is to ensure that a non-discrimination clause on grounds of disability is inserted in the treaty, so that Europe can take legislative and policy action on disability. The Commission's White Paper on Social Policy states "this is an omission that is becoming increasingly difficult to justify in today's Europe". European disability policy is currently limited to programmes because Europe has no legal basis to take other actions. Too often, when disabled people raise problems at European level the response is "this is subsidiarity". Women by comparison have made some progress through having Article 119 in the treaty which has led to directives such as equal pay for men and women. Disabled people cannot challenge discriminatory treatment at European level and cannot have similar directives. The resolution from the Disabled People's Parliament demonstrated that disabled people want more than just action programmes and want equal rights, otherwise Europe will continue to be an economic and financial union and not a citizens' Europe.

The principle of non-discrimination already exists in some national legislatures, most recently in Germany, where the constitution has just been amended. The USA, Australia and New Zealand all have anti-discrimination legislation meaning that disabled people not only have better social rights but that these countries benefit eco-

nomically. Without similar provision, Europe risks being left behind both economically and socially. It is important to distinguish between a non-discrimination clause on grounds of disability and full anti-discrimination legislation. The former simply gives the Union a legal basis for policy and legislative action on disability.

The European Parliament has already begun its discussions on the intergovernmental conference and is championing citizens' rights. So far, committees are giving opinions to the Parliament's Institutional Affairs Committee which will be responsible for making the Parliament's overall report.

Bartho Pronk MEP, an active member of the intergroup, has produced the Social Affairs and Employment Committee's opinion which states that at the beginning of Title VIII on social policy, a reference to the principle of equal treatment, irrespective of race, sex, age, handicap or religion, should be included. The committee's report on the White Paper on Social Policy further "insists on the need to facilitate the integration of disabled people and to take comprehensive measures to outlaw discrimination against such people." The Socialist Group has also stated in its initial approach to the 1996 treaty review conference: "We must strengthen the notion of European citizenship by giving the Union competence to act and to legislate on all forms of discrimination, notably on grounds of colour, religion, or disability."

The European Parliament, however, is only one of the many actors in the discussions on treaty revision, and the key decision-makers will be the Member States' national governments. It will be vital for disabled people at national level to put pressure on their national governments to ensure that disabled people can look to Europe for their rights.

Barbara Schmidbauer

MEP,

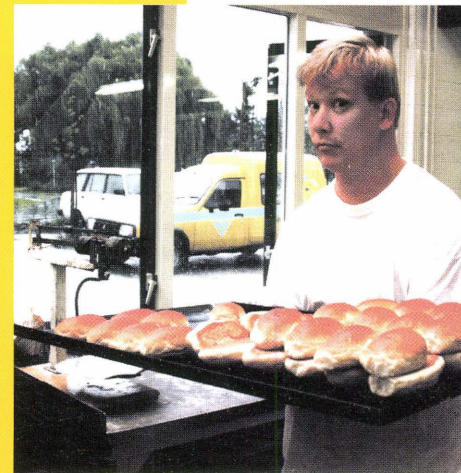
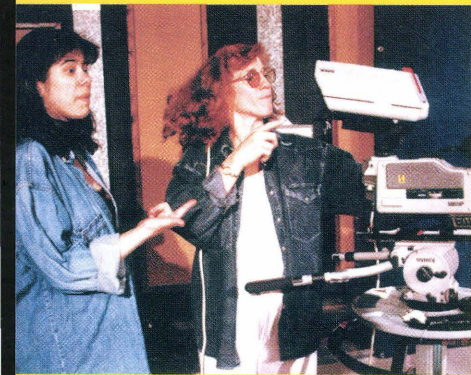
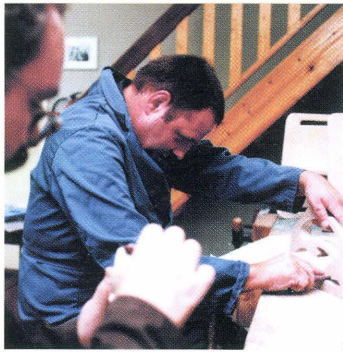
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**independent
living**