CHAPTER 5

Disabled Peoples' International:
Europe and the social model of disability

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Introduction

The term 'social model' is now freely bandied about by governments, policy–makers and all those involved in disability issues. Very few understand what they mean, but the words have become acceptable and people often feel politically correct uttering them. Others – particularly those involved in service provision – see the words as a threat. Academics wrangle over them and most disabled people who are still living lives of isolation, poverty and exclusion are so oppressed by their circumstance that they cannot grasp the implications.

For the purposes of this chapter, I use the social model of disability as the analysis of the situation of a disabled person, defining disability as the relationship between a person with impairment and the environment, including attitudes, beliefs, climate, architecture, systems and services. The social model analysis is the essential political tool of the disability rights movement. It allows activists to clarify exactly what changes and actions are necessary to ensure that disabled people's dignity, rights and freedom are guaranteed. It is important to note the difference between the social model as an analytical tool and the actions then taken for social change. In this new millennium where the words 'human rights' are heard on everybody's lips to cover any or every issue, there has been a tendency to use the term 'human rights model of disability'. This can only muddle and confuse and, inaccurately, turn human rights into an analysis of a relationship instead of what they really are: an agreed code to ensure social cohesion. There has to be clear understanding between the analytical nature of the social model and the actions needed for social change inherent in human rights (Kallen 2004). The two, properly understood and applied together, underpin the

validation of disabled people as an important and discrete group of human beings.

Starting with a quick overview of the importance of the UK disability movement's adoption of the social model and then looking at the history of Disabled Peoples' International in Europe, I hope to illustrate how the social model has impacted on that history and its profound importance as an impetus to political activity, social change and the promotion of civil and human rights for and by disabled people.

UK Experience

Building on a chapter by Paul Hunt (1966) entitled *The Critical Condition*, the analysis of the experience of disability by UPIAS in the mid–1970s is well documented (UPIAS 1975). Although the term social model had already been used in relation to other groups who faced invalidation, such as women and ethnic minorities, these discussions within UPIAS first introduced the concept of the social model with regard to disability and, led by Mike Oliver (Oliver 1990), have since been further expounded and explored by numerous academics. Just as importantly, those disabled people involved in the UPIAS discussions (Ken Davis, Vic Finkelstein, Dick Leaman, among others,) then went on to be in the leadership of disability rights activism and passed their message, energy and experience on to many others at both local and national levels. Their clarity of thought in defining disability ensured that the initial constitution and manifesto of Disabled Peoples' International (DPI) set the right (and the rights) agenda. Discussions between UPIAS members and disability rights activists in North America, Ireland, Finland and Sweden also led to an understanding of Independent Living as a tool for social change.

The Birth of DPI

Why did DPI happen? It happened because disabled people grabbed an opportunity and because, among the 250 disabled people gathered at Rehabilitation International Congress of 2-3,000 non–disabled rehabilitation and charity experts in Winnipeg, Canada, in 1980, there were the thinkers from UPIAS and the independent living activists from North America. Those 250 disabled people, who came from all over the world, recognised their shared exclusion and oppression. They saw the commonality of their discrimination as a people whose humanity was removed. They saw that they should no longer be dehumanised as objects of pity and charity – as consumers of rehabilitation and medical services –

but as people who were born free and equal in rights and dignity. As a result they conceived a worldwide movement which was born a year later in 1981 in Singapore (DPI 1981). The manifesto, constitution, action plan and Congress Declaration agreed in Singapore, all focused on the 'full and equal participation of disabled people in society' and saw the implementation of rights as the solution. DPI moved the definition of disability away from the individual to limitations in society.

The European countries represented at this first congress were: Ireland, Sweden, Norway, Italy, Portugal and the UK. Liam Maguire from Ireland and Bengt Lindqvist from Sweden had been on the Steering Committee and they both went on to the first World Council as officers, with added European representation from Vic Finkelstein from the UK and Ann-Marit Saebones from Sweden. The DPI Constitution required five regional councils: Africa, Latin America, Asia/Pacific, North America and Caribbean, and Europe.

Growth of DPI European Region
Bengt Lindqvist's regional report to the DPI World Congress in 1985 (in the Bahamas) stated that contact had been made with disability organisations in 40 European countries, and they had been invited to a conference and regional assembly in June, 1985. Twenty-three countries sent representatives – from the EU and Central and Eastern Europe – but only the UK, Norway and Sweden had full membership, to be joined immediately by Cyprus and Portugal. Finland and Denmark both fulfilled the requirements of membership but wished to stay as observers. The regional council was elected and an interim working group set up, to which organisations who were not already members of DPI could be invited and who could be asked to take responsibility for further development of the European Region.

Any work carried out in Europe was completely dependent on resources from the individual members. Unlike all the other regions of DPI, there was no central funding for Europe. This omission of Europe from the DPI budget was deliberate. The DPI World Council had agreed that available resources should go to developing countries and considered that there was money available in Europe that could be obtained by the European Regional Council. It took until 1990 for members of the European region to convince the rest of DPI that though there was undoubtedly development money within Europe, very little was available to the development of disabled people's

own organisations and their rights within Europe itself or within the member states.

In the 1980s, Europe – as personified by the European Economic Community – was deeply entrenched in the view of disabled people as objects of charity, rehabilitation, segregation and specialisation. The focus of European Economic Community (EEC) activity with regard to disabled people was through the Bureau for Action in Favour of Handicapped People in the Directorate of Employment, Industrial Relations and Social Affairs (DGV E3), which had two programmes: Helios 1 and Helios 2, both of which were meant to focus on the integration of disabled people in society but which were essentially an exchange of information on local models of excellence. DGV E3 had set up a form of consultation that allowed European Non-Government Organisations (NGOs) concerned with disability to join a Dialogue Group. This met two or three times a year to discuss the Helios programmes. Few of the NGOs consulted were disabled people's own organisations and most representatives were non-disabled people. DGV E3, needless to say, did not employ disabled people and its equivalent unit in the European Union (EU) still does not, to this day.

An important focus for DGV E3 during the last half of that decade was Handynet – a project on which millions of ecu were spent. Handynet was a proposal to develop a series of linked computer accessed data banks to store information aids (in the first instance) and later, other 'disability relevant' information. This project was not going to be easily available or accessible to disabled people and was another tool for rehabilitation professionals and service providers. DPI's criticism of this proposal, as expressed by their representatives at a meeting in Brussels in 1984, was that as all people were aid users, information on aids for disabled people should be integrated within a general data bank on this subject (Leaman 1984) – a social model solution.

Other events taking place during the 1980s of relevance to disabled people were the 1987 European Mid-term Evaluation of the UN Decade of Disabled People in Ljubljana, Yugoslavia, and the World Evaluation of the Decade in Stockholm, Sweden. DPI was represented and played a significant role on both occasions. The outcome of both evaluations was that very little progress had been made toward the objectives of the Decade of full and equal participation of disabled people in society and that disabled people and their organisations were not being resourced or consulted as outlined in the World Programme of Action Concerning

Disabled Persons, the UN agreed proposals for implementing the objectives of the Decade. Indeed, the evaluation showed that most countries in both Europe and the rest of the world were ignoring the World Programme of Action (UN 1987).

Also in 1987, Sweden and Italy spearheaded a proposal at the UN General Assembly for a convention on the rights of disabled people. This proposal had been supported by the UN Experts gathered for the evaluation of the Decade, in particular the DPI representatives. Unfortunately it fell at the first hurdle in New York and alternative proposals were put forward a year or two later to elaborate UN Standard Rules on the Equalisation of Opportunities for disabled persons.

Another important process was started in 1987 at the Stockholm evaluation meeting. The World Health Organization (WHO) held a separate meeting with representatives from the UN Statistical Department and DPI, who were demanding that the WHO revised their *International Classification of Impairment, Disability and Handicap* (ICIDH) (WHO 1980). DPI demonstrated to the meeting how damaging this classification had been to disabled people – primarily because a classification of people took away their identity as fellow human beings – for no other group was a classification based on their personal medical characteristics considered necessary. Also, through assessments for services and benefits, the definition of disability as a medical model only confirmed the supremacy of the medical and rehabilitation professionals as 'owners' of disability issues rather than disabled people having control over their own lives and status as participating citizens and human beings. This, fairly informal, meeting started the slow and tortuous process that eventually led to the new ICF (*International Classification of Functioning, Disability and Health*) being agreed in 2001.

It is interesting to note that the ICF, although still flawed, is now intended to classify a situation and is applicable for everyone. It defines disability as arising from an 'integrative' model – the interaction taking place between functioning and the environment (including systems, attitudes, beliefs and policies). The WHO describes disability as being a socially created problem:

> Disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. Hence the management of the problem requires social action, and it is the collective responsibility of society at large to make the environmental modifications

necessary for the full participation of people with disabilities in all areas of social life. The issue is therefore an attitudinal or ideological one requiring social change, which at the political level becomes a question of human rights. For this model disability is a political issue (WHO 2001).

The WHO goes on to say that the ICF is based on an integration of the two opposing models of the medical and social and uses a 'biopsychosocial' approach – to 'achieve a coherent view of different perspectives of health from a biological, individual and social perspective' (WHO 2001). Put simply (if that is possible with such a complicated procedure) – disability is defined within an integrative model (rather than a medical or social) and their approach to classification is through the three domains of body functions and structures, activities and participation and environmental factors.

If used as now devised, the ICF could be a useful tool for assessments and statistical evidence using a social model approach. However, it does still give the medical professions the opportunity to ignore environmental factors, only use it for disabled people, and just continue to repeat their prejudices of the past. It would have been preferable if DPI could have persuaded the WHO to get rid of the classification altogether but that was impossible, although they did try (WHO 2001). There were far too many medical professionals and policy-makers wanting a structure of analysis for the outcomes of disease.

Independent Living

Many of the people involved in the birth of DPI were also involved in the Independent Living Movement. Independent Living is not just a social movement with a distinct constituency and history but is inextricably entwined with the Disability Rights Movement and is more than a grass-roots effort to acquire new rights, entitlements and services.

The first documented disabled people's self-help organisation emerged in Berkeley, California (Zukas 1979). The University of California was fertile ground for civil rights activists and provided the right environment for a group of disabled students, who were using the hospital wing as their hostel, to assess their own needs and rights and to work out how they could go out into the world, get jobs and live full and active lives.

Their solution was to set up, in 1970, a Centre for Independent Living (CIL), a non-residential facility run by disabled people, providing services and programmes to allow individuals to live independently in the

community. They also provided advice and information on legal and welfare rights, housing, adaptations and access. They had programmes in training, peer counselling, advocacy and independent living skills. Crucially, they also formed a strong pressure group to affect policy on disability issues at the local, state and federal levels.

CILs flourished throughout the USA and Canada and by the mid 1970s disabled individuals from the UK, Sweden, Finland and Japan had heard about or visited the Berkeley CIL and set up their own organisations in the early 1980s. These CILs were not always called that nor did they strictly follow the same formulae. But they were all run by disabled people, for disabled people's rights in their own communities and were a focus for disabled people's own response and contribution to those communities.

It must be remembered that in some European countries, notably Holland and the Nordic countries, the provision of personal assistants and some independent living initiatives had been in place since the 1950s. But none of these services were controlled by disabled people themselves – they were just recipients, without proper choice. The services were given to people with medical conditions as a rehabilitation measure and a social service in the community, not as a right to full citizenship and humanity.

During the 1980s, the Independent Living concept was picked up by many other disabled people in Europe and in 1989 a meeting was held in Strasbourg of all those interested and the disabled delegates produced a position paper on what Independent Living was and its role in promoting rights for disabled people. This was followed by a meeting of DPI (world) Independent Living Committee and Symposium on May 6, 1990 in Lahti, Finland, where the disabled delegates formulated the basic principles of independent living. Working on these basic principles the European Network on Independent Living (ENIL) was born at a meeting in October, 1992 in Berlin. ENIL occasionally manages to obtain funding for training or development projects, but it is essentially a voluntary network to exchange ideas and experiences and now has membership of the European Disability Forum in its own right. And during the 1990s, DPI Europe, in support of ENIL, was able to carry out several Independent Living programmes with funding from the European Commission (DPI 1983-1990).

Funding for DPI – Europe

At last, in late 1990, the World Council of DPI decided to allot US $40,000 to the European Region and a preliminary regional council meeting was

held in Brussels that year to elect officers and agree a way forward. DPI Europe then held a meeting in November, 1991 in Paris to coincide with a Council of Europe Conference of Ministers Responsible for Policies for People with Disabilities. This had focused on Independent Living and had had good input from disabled people.

This DPI Regional Council meeting in Paris was a very productive one. Membership had increased to 14 member organisations including Bulgaria and Poland. It was decided that ENIL should become an Independent Living programme affiliated to DPI/E. It was also agreed to form a separate European Community committee within DPI/E to be formed from the national assemblies whose countries had joined the EC. The committee would be a separate entity but would work closely together with DPI/E to ensure a unified political approach. This committee could also apply for funding from the EU for projects under a new funding programme.

At the same time – the end of 1991, the European Parliament refused to pass the Helios budget. This gave DPI Europe a chance to use its lobbying skills learnt at the international level and they joined with other DPOs to demand a much more democratic consultative mechanism. The outcome was the European Disability Forum in which DPI played a significant role, ensuring that the programmes for disabled people became more centred on human rights and more open to applications from organisations such as DPI Europe.

Further meetings of DPI/Europe and DPI/EUC were held in Birmingham, UK in November 1992 in conjunction with a European Commission financed large conference and exhibition called INFORM 92. Members of other European disability organisations were also invited to a Round Table Conference to see how they could work together more effectively. Meanwhile applications had gone in to the EU for funding for projects on equalisation of opportunities and DPI/EUC were able to employ an experienced disabled person, Arthur Verney, to develop DPI/Europe. With support from a growing staff based in the offices of DAA in London and sharing expertise, DPI/E and EUC then really took off. Membership grew, action plans were agreed and all national assemblies given encouragement and financial support to be active within projects (DPI 1991-2).

At the same time as all the activity at the grass-roots and within the democratic movement, many relationships were being forged with other EU disability organisations and with the Commission. And

there were major changes happening within the whole EEC. The Treaty of Maastricht focused on the European social dialogue and the Agreement on Social Policy was adopted by all member states, except the UK, in 1993.

Using experiences gained from the international movement, through events such as Independence 92 in Vancouver, Canada and the formulation of the *UN Standard Rules on Equalisation of Opportunities for Disabled People* (1993), DP/EUC sought and received considerable funding from the Commission to celebrate the first International Day of Disabled Persons. This day – December 3 – had been announced by the UN as a focus for human rights and disability, at the General Assembly in 1992 to mark the end of the Decade of Disabled Persons (Hurst 1995). DPI/EUC planned a major information campaign to raise awareness of the day with its message of human rights (not rattling charity cans at street corners!) and also arranged a Parliament of Disabled People in the official Parliament chamber of the European Union in Brussels.

Getting agreement to use the official chamber proved very difficult. Twice the College of Questors – the official arbiters of the chamber's usage – denied DPI/EUC the right of access, despite previous *ad hoc* parliaments of students and pensioners. It was only at the third time of asking and threatening direct action within the Parliament building that permission was granted. So on December 3 1992, 440 disabled people from all the EU countries met in the Parliament to debate their human rights. Egon Klepsch, the President of the Parliament opened the proceedings, which were chaired by DPI/EUC. Padraign Flynn, Commissioner for Social Affairs, Members of the European Parliament (MEPs) and Commission officials attended. They were allowed to speak very briefly and to sign an Affirmation of Commitment to disabled people's rights and the UN Standard Rules on Equalisation of Opportunities for Disabled Persons, but their real role was to listen. And listen they did and to a story they had never heard told so vividly before. Eighty of the disabled people got up and each one gave an account of the reality of their lives – they told about the abuse, neglect, segregation and isolation (DPI/E 1993).

Those stories really marked a turning point in disability and the EU. The European Parliament resolved to support the Disabled People's Parliament Resolution to support the UN Standard Rules, to research the real situation of disabled people in Europe and to find out what was happening with the rise of violence and fascism. The Intergroup on Disability of interested MEPs was strengthened and a staff person

employed. The Commission also took more notice of the European Disability Forum (EDF) and raised the amount of funding available for disabled people's projects. The Treaty of Maastricht, by giving social partners, including disability organisations, a voice in introducing new basis for action also put considerable pressure on the European Commission and the other institutions to introduce the notion of non–discrimination. Disabled People's organisations – notably DPI/EUC – pushed for the adoption by the EU of the UN Standard Rules on Equalisation of Opportunities. These were adopted in 1993 and were formally endorsed by the Council in its Resolution of 20 December 1996 on Equality of Opportunity for People with Disability.

Article 13

Having affected a sea change in EU thinking on disability, DPI and the EDF then took a substantive role in lobbying with other social partners to ensure that Article 13 of the next revision – the Treaty of Amsterdam (1997) – provided for appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation. This enables the EU to help national and local agencies to do more on the fundamentals of integration and rights, including for disabled people.   Using Article 13 as a starting point, the Council adopted on 27 November 2000, a comprehensive anti-discrimination package comprising a Directive establishing a general framework for equal treatment in employment and occupation and a Community action programme to combat discrimination, 2001-2006. The Directive provides a legislative framework for legally enforceable employment rights, including provisions on a number of key issues such as protection against harassment, scope for positive action, appropriate remedies and enforcement measures. More importantly, the directive also adopts the duty of reasonable accommodation, which implies the adjustment of the workplace to meet the needs of a disabled person. It was this Directive which ensured that the UK Government altered the Disability Discrimination Act's employment section to include all employers.

In order to fulfil its commitment to Citizenship, the Commission adopted on May 12, 2000, a communication entitled *Toward a Barrier-Free Europe for Disabled People*, in which it commits itself to developing and supporting a comprehensive and integrated strategy to tackle social, architectural and design barriers that restrict access for disabled people to social and economic opportunities. The EDF is now working hard with

the European Parliament to introduce a disability directive which will cover all areas, in the same way as the race directive.

Human Rights

The DPI World Council reaffirmed itself as a human rights organisation in 1992 and agreed a resolution, signed by hundreds of members, to investigate a system to obtain evidence on violations of disabled people's rights (DPI 1992). An initial feasibility study was carried out for DPI by a Canadian lawyer, Yvonne Peters (Peters 1994). The study encouraged the collection of evidence of violations from DPI organisations around the world to be put on a special database. Whilst it was seen as a good idea that DPI should take the lead in planning this and providing the information – it was felt it would be safer for some national assemblies if DPI did not actually manage the database. However, DPI Europe sought and obtained funding from the European Commission to carry out a series of projects with disabled European lawyers in assessing how the evidence should be processed and then collected by disabled volunteers throughout Europe. Several years of thought, discussion and then training resulted in Disability Awareness in Action (DAA) setting up the database in 1999 with initial information from the trained co-ordinators from DPI. The database now has evidence of violations against over two million disabled individuals (1 million plus from Europe) all of which have happened since 1990 and are fully verified. The stark realities of the evidence are that 10% of the cases are of violations to the right to life itself (that is, disabled people are killed just because they are disabled people) and over 34% are of degrading and inhuman treatment (DAA 2003).

Bioethics

Bioethics is another area in which DPI Europe has done some very good work in promoting the social model. As the DPI position paper on Bioethics and Human Rights says:

> From pre-natal screening and the selective termination of 'undesirable' pregnancies to euthanasia of disabled adults, one of the biggest threats to the rights of disabled people this Millennium lies within the field of bioethics – the ethics of advances in biological medicine and science. If disabled people's rights are to be protected, it must be in a context where we are confident that society is willing to share burdens and support

those whose needs are greater than others to ensure equality of
opportunity (DPI/E, 2000).

DPI/E's aims in its Action Plan for 1999-2002 were to influence the
EU, Council of Europe and national government in their way of thinking
on bioethical concerns and to educate disabled people within Europe and
the rest of the world on bioethics. Initial work got together disabled
people from all over Europe to formulate the position paper and then to
provide training so that disabled individuals could become articulate on the
issue and be used as experts by their national bioethics committees.

There is no doubt that the new genetic sciences are a real threat to
disabled people's humanity. The social model has flown out of the window!
In genetic terms we are only seen as impaired genes and the outcomes of
allowing these genes to multiply into a living person are unreasonable in
terms of social support, health costs, individual pain and suffering and
intolerable quality of life. This allows the massive rejection of embryos
which may have impairments, late abortion on the grounds of impairment,
pressure on parents to think they are producing a child whose life is not
worth living – or, as one doctor said to a mother whose foetus had been
diagnosed as having Down's Syndrome, 'your child will not be worth
loving' – and increasing legislation in support of assisted suicide. There is
neither discussion of the prejudicial and discriminatory nature of such
quality of life assessments nor of the basic right to life of all human beings,
regardless of impairment. There is no acceptance that the right to life of a
viable foetus should take precedence over the right of a mother to choose.
Nor is there admission that these late foetuses are not aborted until they
have already been directly killed in the womb so that there is no danger of
them living. There is little realisation that disabled people's quality of life is
dependent on choice, control, proper access and support – just like
everyone else. There is nothing 'special' about our needs, they are just
different. By saying that the costs of our needs are too much or too
difficult, society is denying that we are citizens for whom they have a
responsibility. And there is little acknowledgement of the eugenic nature
of these bioethical practices and the threat to our fundamental
human rights.

End of DPI/E Funding

A circle seems to have formed with regard to DPI/Europe's funding. Due
to the suspension of funding for all EU disability projects for a whole year,
delays and audits by the Commission resulting in non-receipt or demands

for repayment of final payments for projects as far back as 1999, DPI Europe had to close its books in the UK in May 2003 and was unable to continue its planned projects after 2002 or employ any staff. However, DPI Europe still has an active Executive Committee and is a member of the EDF. Its national assemblies have taken on some of the plans that were planned. For instance, the national assembly in the UK (the British Council of Disabled People) has obtained funding for training in bioethics. There is a DPI office in Hungary for Central and Eastern Europe. But there are only the small annual allocations from DPI HQ to ensure that the democratic mechanism can function.

Conclusion

Primarily through the activities of the disability movement, the social model has flourished in Europe in the last decade, combined with recognition of disability as a human rights issue. There has been real progress away from the rehabilitation, charity models, to an understanding of inclusion, choice and control for the individual. You could say that the social model rules OK. But does it? There are threats – the obvious one of bioethics, but there is the less obvious one of argument among academics of what the social model is and who owns it which allows policy-makers (for instance WHO) to ignore it and invent their own language. However, the greatest threat is to the voice of disabled people and to our status. The silencing of DPI through lack of funding, the absence of disabled people on bioethics committees and in political leadership, the growth in eugenics, all put us back into that box of 'other' and 'special' and emphasise our lack of citizenship and invalidity.

We must find new ways of working toward social change. We must form new alliances to raise the profile of disabled people. Those alliances, must, however, be alliances of equals. We must shout from the rooftops about the reality of our lives and the endless and horrific violations of our rights but we must shout equally loudly about our contributions – how Europe cannot do without us – how services and policies that include disabled people are better for everyone. And the disabled person's voice must be given its rightful status. It is a disgrace that there are no disabled people in DGV E3 – the Women's Unit would not employ a majority of men. It is a disgrace that government representatives discussing disability issues are not prominent disabled people. We need it to be fully recognised that if any piece of knowledge or happening or service or policy has a disability perspective, then disabled people must be there, giving that perspective and

our time and expertise properly compensated. And the reality is that everything is about us – as it is about every single individual. Planning society does not work for anybody if the rights and needs of the individual are ignored and their participation not recognised. We each have equal worth. The social model clarifies what we are – human beings with rights. And the social model analyses the barriers to our accessing our full humanity. The social model must continue to 'rule OK' and be implemented through a human rights framework of equality, dignity and freedom.

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