# The EU Rights Based Approach to Disability Some Strategies for Shaping an Inclusive Society

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#### 1. Introduction

The past ten years have witnessed a marked change in the legal and policy responses of many European countries, and of the EU itself, to the issue of disability. This new (and still emerging) response is often termed the 'rights based approach'. In this paper I will attempt to clarify the nature of this approach and to suggest a number of ways in which disability organisations might work towards establishing it in their own countries. My starting point will be a brief examination of the more traditional approach to disability, however, as it is difficult to grasp the essence of the new approach without an appreciation of its contrast with the old.

## 2. The Traditional Approach to Disability

Traditional legal and policy responses to disabled people have been shaped by an understanding of 'disability' which has become known as the 'medical' or 'individual' model. On this view people with physical, sensory or mental impairments causing some sort of loss of function are prevented or 'disabled' from leading normal lives or participating in normal society by that functional loss: because they cannot climb steps, they cannot go to the gym or enter the local shop; because they cannot hear, they cannot participate in seminar discussions or follow a film in the cinema; because they cannot see, they cannot read their school books or their telephone bills. Disability, on this understanding, is seen as a problem located within the individual. Unless that individual can be cured or somehow adapted, they will not be able to participate in the life of mainstream society. It is they that must change or be changed in order to fit within a society designed for non-disabled people.

studies/archiveuk/finkelstein/soc%20mod%20repossessed.pdf

<sup>&</sup>lt;sup>1</sup> M Oliver 'The Politics of Disablement' (Basingstoke, Macmillan, 1990); M Oliver 'Understanding Disability: From Theory to Practice' (Basingstoke, MacMillan, 1996); M Priestley 'Constructions and Creations: Idealism, Materialism and Disability Theory' (1998) 13 Disability & Society 75; V Finkelstein 'The Social Model of Disability Repossessed' (paper presented to Manchester Coalition of Disabled People, 1 December 2001) available at http://www.leeds.ac.uk/disability-

Correction (by aids such as spectacles, hearing aids); the provision of mobility aids (such as wheelchairs, guide dogs and long canes) and assistive technology (such as speech synthesisers); and rehabilitation (by the provision of training in life skills such as cooking); have often received considerable emphasis where the individual model of disability is predominant. Effective policies in these areas will play a vital role in any society in enabling disabled people to live independently. Traditionally, however, such services have tended to be delivered and administered by non-disabled 'experts' with the expectation that disabled people will be passive recipients having little influence over decisions and priorities. Further, no matter how effective policies in these areas might be, many disabled people cannot be squeezed into narrow conceptions of normality. No matter how well designed a wheelchair might be it will not allow its user to negotiate steps with ease. No matter how well trained a guide dog might be it will not enable its owner to read printed labels on tins of food in supermarkets

A predictable consequence of a medical model understanding of disability is the segregation of disabled people. If they cannot be made normal then they must remain abnormal outsiders unable to cope with the real world. Consequently, in many countries a separate or parallel track was established for disabled people who were thereby segregated from the mainstream.<sup>2</sup>

At its most extreme this parallel track would result in disabled people living in institutions which have been specially adapted for their needs and where they will be 'cared' for. The distress and humiliation caused by such enforced segregation is sometimes intensified by neglect and a disturbing lack of care.<sup>3</sup>

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<sup>&</sup>lt;sup>2</sup> See discussion in L Waddington and M Diller 'Tensions and Coherence in Disability Policy: The Uneasy Relationship Between Social Welfare and Civil Rights Models of Disability in American, European and International Employment Law' in M Breslin and S Yee (eds) 'Disability Rights Law and Policy: International and National Perspectives' (Ardsley New York, Transnational Publishers inc, 2002)

<sup>&</sup>lt;sup>3</sup>See eq. (in relation to the UK) DHSS 'Report of the Committee of Enquiry into the Allegations of Ill-treatment and Other Irregularities at Elv Hospital. Cardiff' (Howe Report) Cmnd 3785 (London, HMSO, 1969); M Oswin 'An historical perspective' in C Robinson and K Stalker (eds) 'Growing Up with Disability' (London, Jessica Kingsley Publishers, 1998); and R Daw 'The Impact of the Human Rights Act on Disabled People' (Disability Rights Commission and Royal National Institute for Deaf People, London, 2000). See also ST Herr, L Gostin and H Koh (eds), 'The Human Rights of Persons with Intellectual Disabilities' (Oxford University Press, Oxford, 2003) particularly chs 4 and 5; O Lewis, 'Mental Disability Law in Central and Eastern Europe: Paper, Practice, Promise', (2002) 8 Journal of Mental Health Law, 293; and International: Europe Bulgaria 2002 http://web.amnesty.org/web/ar2002.nsf/eur/bulgaria

A less extreme example of the segregating effect of this parallel track for disabled people is special education. Many countries have invested in the provision of schools in which the teaching and the extra-curricula activities are organised specifically to cater for the needs of children with particular impairments. While some such schools may enable disabled children to attain a standard of education higher than that which they would have attained in a mainstream school not adapted to meet their needs, academic achievement is often not given a high priority.<sup>4</sup>

This type of segregation has also been evident in the employment field. Policies have frequently been developed on the assumption that disabled people will not be capable of working in mainstream environments and should therefore be catered for through sheltered employment schemes. These are generally subsidised by the state and offer work which is usually low paid and unskilled.<sup>5</sup>

Another common European response to disability in relation to employment, which again presupposed the inability of disabled people to compete on the open job market, was the imposition of quota systems. These proliferated after the Second World War and encouraged or obliged employers over a specified size to ensure that their work force contained a certain minimum percentage of disabled employees. Though there were often mechanisms whereby the state could enforce these quotas, or impose penalties on employers for noncompliance, in the UK and elsewhere such mechanisms were rarely used. Quotas were not enforceable by disabled people themselves and would be satisfied in cases where disabled employees were clustered in low status and poorly paid roles.<sup>6</sup>

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<sup>&</sup>lt;sup>4</sup> See generally M Corker and JM Davis 'Disabled Children: (Still) Invisible Under the Law' in J Cooper (ed, Law) 'Law, Rights & Disability' (London, Jessica Kingsley Publishing, 2000); L Middleton 'Disabled Children: Challenging Social Exclusion' (Oxford, Blackwell Science, 1999); G Hales (ed) 'Beyond Disability, Towards an Enabling Society' (London, Sage Publications, 1996); and K Lundgren 'Ake's Book' (Stockholm, Riksforbundet FUB, 1993).

<sup>&</sup>lt;sup>5</sup> For a general review of employment policies relevant to disabled people see P Thornton and N Lunt 'Employment Policies for Disabled People in Eighteen Countries: a review' (Social Policy Research Unit, University of York, 1997).

<sup>&</sup>lt;sup>6</sup> See generally L Waddington 'Legislating to Employ People with Disabilities: The European and American Way' [1994] 1 Maastrict LJ 367; and L Waddington and M Diller 'Tensions and Coherence in Disability Policy: The Uneasy Relationship Between Social Welfare and Civil Rights Models of Disability in American, European and International Employment Law' in M Breslin and S Yee (eds) 'Disability Rights Law and Policy: International and

Disabled people then, if fortunate enough to secure employment at all, would generally find themselves in positions with very low wages. The link between poverty and disability is well-established. Because of this disabled people have often become heavily dependent on assistance from charity or benefits. Western European states traditionally developed fairly generous social welfare systems to support people with impairments who found themselves on the parallel, nonmainstream track. These undoubtedly played an essential part in ensuring that disabled people did not starve or freeze and that their basic needs were generally met. However, they were frequently grounded on the assumption that disabled people were incapable of work and tended to foster exclusion and dependence.8

## 3. The Rights Based Approach to Disability

Key to a rights based approach to disability is the idea that the inability of disabled people to participate fully in the life of their communities is not to be attributed solely to the limitation of function resulting from their impairment. Societal factors operate to exclude them. These include the design of buildings and vehicles, the structure and operation of organisations, and the hostile or mistaken attitudes of individuals towards them. The importance of these social factors in the exclusion of people with impairments is highlighted in the social model which reserves the term 'disability' specifically for exclusion resulting from societal barriers.9

On this view, then, the disabling, exclusionary barriers which should be tackled by laws and policies lie outside the individual. It is because the gym and the local shop do not have a ramp or a lift that a person with a mobility impairment cannot enter; because there is no loop system or signing service that a deaf person cannot participate in seminar

National Perspectives' (Ardsley New York, Transnational Publishers inc, 2002).

<sup>7</sup> See, eg, discussion in C Barnes 'Disabled People in Britain and Discrimination: a Case for Anti-Discrimination Legislation' Hurst/BCODP, 1991), ch 5.

<sup>&</sup>lt;sup>8</sup> See in particular A Hendriks 'From Social (In)Security to Equal Employment Opportunities: A Report from the Netherlands' in M Jones and LA Basser Marks (eds) 'Disability, Divers-ability and Legal Change' (London, Martinus Nijhoff, 1999); and L Waddington and M Diller 'Tensions and Coherence in Disability Policy: The Uneasy Relationship Between Social Welfare and Civil Rights Models of Disability in American, European and International Employment Law' in M Breslin and S Yee (eds) 'Disability Rights Law and Policy: International and National Perspectives' (Ardsley New York, Transnational Publishers inc, 2002).

<sup>&</sup>lt;sup>9</sup> See above n 1.

discussions or follow a film in the cinema; and it is because materials are not provided in alternative formats that a blind person is unable to read their school books or their telephone bills.

As is well known, disabled people themselves have played a leading role in the development of the social model of disability. Its origins are often traced to the following words of the Union of Physically Impaired Against Segregation:

'In our view, it is society which disables... Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.'<sup>10</sup>

Disability activists, influenced by this understanding of disability, have therefore campaigned for laws and policies designed to tackle the socio-economic and attitudinal barriers lying at the root of the exclusion of people with impairments. At the EU level this is illustrated by a resolution passed by the first European Disabled People's Parliament on 3 December 1993 which called for anti-discrimination legislation and other measures to ensure that:

'disabled people should be guaranteed equal opportunity through the elimination of all socially-determined barriers, be they physical, financial, social or psychological, which exclude or restrict full participation in society'.

What they called for, then, was a new approach to disability grounded on the conviction that disabled and non-disabled people should be equally valued: an approach focusing on the need to adapt society so as to enable (rather than disable) people with impairments.

#### 4. EU Legal and Policy Responses

#### 4.1 Background

Underlying the Council of the European Communities' action plan for the rehabilitation of disabled workers in 1974 was the traditional medical or individual understanding of disability.<sup>11</sup> Gradually, however,

<sup>&</sup>lt;sup>10</sup> 'Fundamental Principles of Disability' (London, UPIAS/ Disability Alliance, 1976) p3.

<sup>&</sup>lt;sup>11</sup> Council Resolution of 27 June 1974, establishing the initial community action programme for the vocational rehabilitation of handicapped persons. See, in particular, the pre-amble where « handicap » is defined as

<sup>&</sup>quot;any limitation, congenital or acquired, of a person's physical or mental ability which affects his daily activity and his work by reducing his social contribution, his employment prospects, his ability to use public services".

the emphasis shifted from policies grounded on the belief that the problem to be addressed lay within the individual towards policies aimed at tackling the societal forces which operate to marginalise disabled people. This is stressed in the Commission's 2003 Action Plan which states that:

"The EU ... sees disability as a social construct. The EU social model of disability stresses the environmental barriers in society which prevent the full participation of people with disabilities in society. These barriers must be removed ..."<sup>13</sup>

This Action Plan details a wide range of ways in which the Commission is working to bring about the removal of these barriers. It is not the role of this paper to set these out in detail but, in order to explain how disability organisations might work towards that same end, I will say a few words about the three key 'operational objectives' identified in that Plan: anti-discrimination, mainstreaming and accessibility. I will also consider briefly the relevance of human rights law to the development of a rights based approach to disability. Anti-discrimination legislation and human rights instruments, which often confer rights on individuals directly enforceable in the courtroom, will be considered first. Mainstreaming and policy initiatives designed to improve accessibility represent other important ways in which barriers to inclusion may be tackled.

#### 4.2 Anti-Discrimination

The adoption of Article 13 represents a landmark development in the context of EU activity in the area of anti-discrimination law. It was inserted into the EC Treaty by the Treaty of Amsterdam in 1997 and granted competence to the European Council to take appropriate steps to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation. In 2000 this new competence led to the adoption of the Framework Equal Treatment Directive (FETD)<sup>14</sup> which requires States to take measures, by the end of 2006 at the latest, to prohibit various forms of discrimination on grounds of disability (as well as religion, belief, age and sexual orientation). It will

Global: Subsidiarity, Transnational Networks and the Making of European Disability Policy' Journal of European Social Policy (forthcoming).

See generally D Mabbett 'The Development of Rights-Based Social Policy in the European Union: the Example of Disability Rights' (Brunel University, 2003) available at http://www.brunel.ac.uk/depts/govn/research/Development\_of\_Rights-based\_Policy\_Bham22Jan.doc; and M Priestley 'Between National and Clabel' Subsidicity' Transportional Nativerses and the Making of European

<sup>&</sup>lt;sup>13</sup> 'Equal Opportunities for People with Disabilities: a European Action Plan' COM/2003/650 final, p 4.

<sup>&</sup>lt;sup>14</sup> Council Directive 2000/78/EC.

ensure that disabled individuals will have enforceable rights to be free from certain forms of discrimination in certain contexts. The FETD is an extremely important development in EU disability policy but a detailed examination of it falls outside the scope of this paper. Two points, however, should be stressed here:

First, the FETD applies only in the context of employment and occupation. It therefore stands in sharp contrast to the other Art 13 directive, the Race Directive, which applies to social protection, education, housing and goods and services as well as employment. Member States are therefore not currently obliged to consider measures aimed at combating disability discrimination in these other extremely important non-employment fields.

Second, despite the Directive's name, it does not simply require that a disabled person should be treated in exactly the same way as a non-disabled person. This is because it is not confined to prohibiting direct discrimination (the less favourable treatment of a person on grounds of disability) but extends to indirect discrimination and also requires reasonable accommodation to be made for disabled people.

Indirect discrimination will occur if an apparently neutral provision criterion or practice is applied to all but imposes a particular disadvantage on disabled people which cannot be justified.<sup>17</sup> Such a provision, criterion or practice should not be applied in the same way to a disabled person. An example might be the application of a 'no dogs' rule to the owner of a guide dog or a requirement that a job applicant hold a driving licence.

Under Art 5 employers are required to adopt measures where they would be needed in a particular case to enable a disabled person "to have access to, participate in, or advance in employment, or to training, unless such measures would impose disproportionate burden on the employer". Where such measures would not impose a disproportionate burden, a failure to take them would thus itself constitute unlawful discrimination. No guidance as to the meaning of 'reasonable' or 'undue hardship' is provided; though in time clarification will no doubt emerge from the European Court of Justice. Whether a measure will be considered an undue burden is likely, however, to depend on factors such as the size and wealth of the employer. Bearing this in mind, employers may be required to make adjustments such as distributing materials to employees in advance of meetings, or reading them out during the meeting, so as to enable visually impaired employees to be fully informed; scheduling events in accessible ground floor rooms so as to enable employees with mobility

<sup>&</sup>lt;sup>15</sup> See further R Whittle 'The Framework Directive for Equal Treatment in Employment and Occupation: An Analysis from a Disability Rights Perspective' [2002] ELR 303

<sup>&</sup>lt;sup>16</sup> Council Directive 2000/43/EC

<sup>&</sup>lt;sup>17</sup> Art 2(2)(b).

impairments to participate in them; providing equipment such as an accessible phone for an employee with a hearing impairment or a speech synthesizer for an employee with a visual impairment required to use a computer; installing alternative lighting in the office of an employee with conditions such as epilepsy; and allowing an employee with an impairment which requires frequent visits to the toilet to have shorter but more frequent breaks.

Thus, the model of equality underlying the FETD is not a strict model of formal equality based on treating people with no relevant difference in the same way. It reaches beyond this, towards some notion of substantive equality, by requiring that some attempt be made to remove some of the barriers which exclude and disable people with impairments. Its reach is severely and disappointingly limited, however, by its restriction to employment.

## 4.3 Human Rights

The European Convention on Human Rights 1950 confers important rights, enforceable in the Strasbourg Court of Human Rights, on citizens in all signatory States. Article 14 confers a right not to be discriminated against in the enjoyment of Convention rights and Protocol 12, if ratified, would confer a more general right to be free from discrimination. The concept of discrimination which has emerged from the Art 14 cases, however, is narrow and has not yet offered a great deal of assistance to disabled people. Nevertheless, other rights (such as the right not to be unlawfully detained contrary to Art 5, the right to be free from torture, inhuman and degrading treatment under Art 3, and the right to respect for one's home and private and family life under Art 8) have an important role to play in protecting the dignity and independence of disabled people.

The revised European Social Charter 1996 confers on disabled people in signatory States, a right to "independence, social integration and participation in the life of the community" and requires those States to take measures to:

'promote their full social integration and participation in the life of the community, in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure.'<sup>18</sup>

<sup>&</sup>lt;sup>18</sup> Article 15.

Unlike the European Convention on Human Rights, however, this Charter has been signed by only a small number of States and its rights cannot be enforced directly by individuals.<sup>19</sup>

At the UN, work is currently underway to build on the 1993 Standard Rules for the Equalisation of Opportunities for Persons with Disabilities<sup>20</sup> and to develop a Convention dealing specifically with the human rights of disabled people. The European Commission has taken steps, under Art 13, to support this work.<sup>21</sup> Though these international covenants will not be directly enforceable by individuals, they will be highly influential both at the EU level and within Member States. Indeed, the European Court of Justice has been keen to assert that human rights derived from such instruments are observed as they form part of the general principles of Community law.<sup>22</sup>

### 4.4 Mainstreaming

This refers to the inclusion of disability perspectives across all areas of EU policy making. Thus, the aim is to incorporate disability issues into mainstream policies rather than to segregate them into an isolated, independent policy sphere. They have therefore influenced policies in fields such as public procurement rules, telecommunications standards, and health care. The Commission's 2003 Action Plan indicates that its efforts in this regard will be concentrated particularly on ensuring the

<sup>&</sup>lt;sup>19</sup> T Novitz 'Are Social Rights Necessarily Collective Rights? A Critical Analysis of the Collective Complaints Protocol to the European Social Charter' [2002] European Human Rights Law Review 52. <sup>20</sup> According to Rule 15:

<sup>&</sup>quot;States have a responsibility to create the legal basis for measures to achieve the objectives of full participation and equality for persons with disabilities . . . States must ensure that organizations of persons with disabilities are involved in the development of national legislation concerning the rights of persons with disabilities, as well as in the ongoing evaluation of that legislation . . . Any discriminatory provisions against persons with disabilities must be eliminated. National legislation should provide for appropriate sanctions in case of violations of the principle of non-discrimination . . . "

<sup>&</sup>lt;sup>21</sup> European Commission Communication 'Towards a United Nations legally binding instrument to promote and protect the rights and dignity of persons with disabilities' COM (2003) 16 final of 24.1.2003.

<sup>&</sup>lt;sup>22</sup>E.g. Case 29/69, Stauder v City of Ulm, Case 4/73 ECR [1969] 00419, Nold v Commission, Case C-60/00 ECR [1974] 00491, Case C-60/2000, Mary Carpenter v Secretary of State for the Home Department ECR [2002] I-006279

inclusion of disability perspectives in employment related policies, especially in education and lifelong learning.<sup>23</sup>

## 4.5 Accessibility

Much work has already taken place at EU level to promote the principle of 'universal design'.<sup>24</sup> In particular, technical access standards have been drawn up to ensure that various types of public transport vehicle will be designed and constructed so as to facilitate their use by disabled people.<sup>25</sup> In relation to the design and construction of the built environment (particularly in the context of work environments, leisure, culture and education) some work has already taken place<sup>26</sup> and more is promised.<sup>27</sup>

# 5. Possible Strategies for Disability Organisations in Promoting a Rights Based Approach

#### 5.1 Internal Reform

Disability organisations have played a leading role in promoting rights based models both within the EU and beyond.<sup>28</sup> An essential preliminery to the success of many such organisations as campaigners for broader legal and social change was internal reform. This occurred as a result of

<sup>&</sup>lt;sup>23</sup>'Equal Opportunities for People with Disabilities: a European Action Plan' COM/2003/650 final, p 13.

<sup>&</sup>lt;sup>24</sup> Council of Europe Resolution of 15.2.2001 on the introduction of the principles of universal design into the curricula of all occupations working on the built environment.

<sup>&</sup>lt;sup>25</sup>See European Commission 'White Paper on European Transport Policy for 2010: a time to decide' COM (2001) 370 final. See generally A Lawson and B Matthews 'Dismantling Barriers to Transport by Law: The European Journey' in C Barnes and J Merser (eds) 'Disability Policy and Practice: Applying the Social Model' (Leeds, Disability Press, forthcoming).

<sup>&</sup>lt;sup>26</sup> Council Resolution of 6 May 2003 on accessibility of cultural infrastructure and cultural activities for people with disabilities (OJ C 134, 7 June 2003); and Council Resolution of 21 May 2002 on the future of European tourism (OJ C 135, 6 June 2002).

<sup>&</sup>lt;sup>27</sup> 'Equal Opportunities for People with Disabilities: a European Action Plan' COM/2003/650 final, para 3.24.

See generally J Campbell and M Oliver 'Disability politics: Understanding our past, changing our future' (New York, Routledge, 1996); R Olson, D Penna and M Veith 'The Disability Movement in Europe' (paper delivered at the Western Political Science Association Meeting, Denver, Colorado, 27-30 March 2003); and R Olson, D Penna, and M Veith 'The Evolution of the European Disability Movement' (paper delivered at the International Studies Association Annual Convention, Montreal, Canada, March 2004).

pressure from disabled people who argued that organisations claiming to represent their interests should be controlled by, and responsible to, disabled people themselves. The process, often termed 'democratisation,<sup>29</sup> went hand in hand with the establishment of umbrella organisations such as Disabled People's International,<sup>30</sup> the British Council of Disabled People, and now the EU funded European Disability Forum. Disability organisations may join these umberella organisations but only if they are judged to be sufficiently 'democratic' in this sense – which generally requires demonstrating that disabled people must have at least 51% of the vote.

This democratisation process is fundamental to effective campaigning for a rights based approach to disability. Without it, disability organisations themselves are likely to send out a message which runs directly counter to the approach for which they are campaigning: a message that disabled people are passive recipients of care and charity, to be looked after by others and not to be troubled by the need to make decisions.

# 5.2 Influencing Impairment-Related 'Rehabilitation', Aids and Services

The focus of this type of intervention is on fitting the individual for society rather than on fitting society for the individual. Concentrating on it to the exclusion of policies aimed at adapting society is therefore inconsistent with a rights based approach to disability. However, it should not be forgotten that this type of service plays a vital part in facilitating the independence of people with impairments and will continue to do so even when the society in which they operate has been adjusted so as to facilitate inclusion – we will still need our guide dogs, our long canes, our wheelchairs and hearing aids. Instead of being expected to accept these services unquestioningly with gratitude, however, disabled people should be permitted and encouraged to play an active part in their development and delivery. The well known maxim of the disability movement:

'Nothing about us without us'

is particularly relevant in this context. Disability organisations are well placed to work towards this end.

#### 5.3 Mainstreaming and Removing Barriers at Source

<sup>29</sup> J Campbell and M Oliver 'Disability politics: Understanding our past, changing our future' (New York, Routledge, 1996) 22.

<sup>&</sup>lt;sup>30</sup> D Drieger 'The Last Civil Rights Movement: Disabled Peoples' International' (New York, St Martins Press, 1989).

Disability organisations should work to promote mainstreaming of disability issues, along the lines adopted by the EU, within their own countries. This should occur in the development of national policy but also at the more local level. Ensuring that committees with policy making roles in fields such as planning, transport, education and health have representation from organisations of disabled people is often a helpful start.

Consideration might also be given to campaigning for a legislative requirement, such as the one likely to be introduced in the UK, to place a positive duty on public authorities to promote disability equality.<sup>31</sup> This would oblige them to consider the impact of all aspects of their design and operation on disabled people and to draw up plans for minimising any exclusionary or unfavourable consequences.

### 5.4 Lobbying

## 5.4.1 For Full Implementation of the FETD in National Law

Disability organisations have an important role to play in working with national governments to ensure that legislation is enacted, if not already in place, which complies with the FETD's requirements in relation to disability. Useful support in this role may be gained from the European Disability Forum and from disability organisations in other countries where legislation has already been introduced.

# 5.4.2 For National Law to Extend Beyond the Scope of the FETD

The FETD lays down minimum requirements only. Since legislative action is likely to be needed in order to comply with it, it would be worth investing energy and expertise into a campaign for that legislation to provide greater protection than that actually required. For instance, the legislation relating to disability (and the other grounds covered by the FETD) could be drafted so as to prohibit discrimination in all the areas in which it must be prohibited in relation to race. Thus, instead of confining it to employment, arguments should be made for a more consistent scheme which would also extend to areas such as education, housing and goods and services. Unless legislation prohibits discrimination in these areas there is a danger that disabled people will be prevented from using accessible public transport vehicles or buildings by a simple refusal of organisations to allow them entry or to make reasonable adjustments in the form of providing them with assistance or information.

<sup>&</sup>lt;sup>31</sup> Draft Disability Discrimination Bill 2003. See generally C O'Cinneide 'A New Generation of Equality Legislation: Positive Duties and Disability Rights' in A Lawson and C Gooding 'Disability Rights in Europe: From Theory to Practice' (Oxford, Hart Publishing, 2005).

#### 5.4.3 For State-Funded Support and Enforcement Bodies

There is no requirement under the FETD for Member States to set up independent enforcement bodies charged with tasks such as providing advice to victims of discrimination and others; providing support to litigants in key cases; monitoring the effectiveness of the legislation and advising the government on desirable changes. Such a body is required, however, in relation to race and to gender. Again, therefore, disability organisations should lobby energetically for the establishment of such a body to cover disabled people. The UK's Disability Rights Commission has undoubtedly played a key role in enforcing and developing the rights of disabled people under the Disability Discrimination Act 1995. Unfortunately, however, the support it is able to offer to disabled victims of human rights abuses falling outside the scope of the DDA is extremely limited. Disability organisations should argue strongly against such restrictions being placed upon the powers of any such enforcement body. Once such a body is established then disability organisations should, of course, work closely with it to maximise the effectiveness of legal protection.

### 5.5 Raising Awareness

### 5.5.1 Amongst Disabled People

Whether or not in conjunction with an enforcement body, disability organisations should work hard to ensure that disabled people are made aware of their basic human rights and of their right to be free from discrimination. Without such awareness it is extremely difficult to challenge injustice, exclusion and abuse. A guide has recently been produced in Finland which is intended to alert disabled people to types of behaviour or situations which may constitute breaches of their human rights or be discriminatory against them. Such efforts could be replicated elsewhere and publicised appropriately (and accessibly) to reach their intended audiences. Potential victims of such infringements should also be made aware of methods by which they might seek relevant legal advice and obtain financial or emotional support.

Article 12 of the FETD imposes a duty on States to disseminate information to all those affected about the requirements of the Directive. Disability organisations may therefore be able to form useful partnerships with State authorities (or obtain funding from the latter) in relation to promoting awareness.

#### 5.5.2 Amongst Employers and Others

Similarly, it is important that employers and others to whom the legislation might apply (such as providers of goods and services) are made aware of their obligations to treat disabled people with respect and

to take steps to accommodate their needs wherever this would be reasonable. Indeed, efforts should be made to increase awareness amongst the public generally and to encourage an understanding that the segregation and exclusion faced by disabled people may result from limitations in society (which it might be possible to alter) rather than from limitations in the particular individuals concerned.

## 5.6 Monitoring and Identifying Potential Improvements

Disability organisations are uniquely placed to perform the important task of monitoring the impact of any rights based law or policy on the lives of disabled people. They should gather evidence demonstrating areas in which exclusion and disadvantage continue. Only if such areas are identified and documented will it be possible to mount effective campaigns for improved laws and policies.

Further, Article 9(2) of the FETD requires States to ensure that 'associations, organisations or other legal entities', having a 'legitimate interest', may engage in any national mechanism set up for enforcing the FETD either 'on behalf or in support of' a complainant. Disability organisations are likely to be able to demonstrate such a 'legitimate interest' and, particularly in countries where there is no relevant independent enforcement body, should develop strategies for using this power to maximum effect. This would involve identifying and supporting cases likely to establish useful precedents resulting in significant changes on the ground.

Part of this monitering role should, therefore, involve tracking legal developments. Not only will this be a prerequisite of drawing up effective strategies relating to supporting potential litigants but it may also provide invaluable publicity opportunities. The failure of a case brought by a disabled person may well provide a focus for a campaign for legal reform. An example of this is the successful campaign of disability organisations in Ireland in 2001 following the failure of a case (in the Irish Supreme Court<sup>32</sup>) concerning the obligation of the State to provide adult education to an autistic man.<sup>33</sup>

<sup>32</sup> Sinnott v Minister of Education, 12 July 2001.

<sup>&</sup>lt;sup>33</sup> See G Cunningham and G McKenna 'Defeat turns to victory.' Irish Independent, 13 July 2001; and discussion in R Olson, D Penna and M Veith 'The Disability Movement in Europe' (paper delivered at the Western Political Science Association Meeting, Denver, Colorado, 27-30 March 2003).

## 5.7 Developing links

It scarcely needs saying that the effectiveness of disability organisations in promoting a rights based approach to disability will be immeasurably enhanced if those organisations develop close links with others. In particular, links with other disability organisations within their own country and outside are likely to prove invaluable in terms of strengthening and targeting campaigns. Membership of existing umbrella organisations (such as the European Disability Forum and the Disabled Peoples International) would provide an obvious means of forging such links on an international level. On a national level, consideration might be given to the establishment of umberella organisations such as the British Council of Disabled People.

Links with organisations which campaign for equality for other traditionally disadvantaged groups (such as women, members of racial or ethnic minorities and people who are gay or bi-sexual) are also likely to prove fruitful. Through the development of links such as these disability organisations will be able to gain insights into campaigning strategies which have proved successful when used elsewhere and to consolidate the campaign for a society based on inclusion and diversity.

#### 6. Conclusion

In this paper I have attempted to identify some of the strategies which might be employed by disability organisations to promote a rights based approach in countries where such an approach has not yet emerged. Which strategies will be available to, and effective for, a particular organisation at any particular time will depend on a wide range of factors - both internal and external. I have concentrated here on strategies which assume the possibility of dialogue and discussion with State authorities. Such dialogue is not always possible and, both in the US and in Western Europe, disability organisations have therefore resorted to gaining publicity through various forms of public protest and direct action. Whatever strategies are adopted, disability organisations have a key role to play in the struggle to achieve a society in which people with impairments are able to participate to the full and in which they are valued as equals. Such a society would necessarily be grounded on a rights based approach to disability. In order to achieve it, efforts must be devoted, not to making us as disabled people fit for society (or to compensating us with welfare benefits for our functional limitations), but to making society fit for us.