EUROPEAN SOCIAL NETWORK

Managing diversity in public health and social care in the interest of all citizens

Report II: Disability

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Dublin, September 2003

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Preface

This report on disability is part the European Social Network project *Managing diversity in public health and social care in the interest of all citizens.* The project seeks to address three interconnected problems, namely:

1. **The experience of those representing groups subject to discrimination is that health and social care services, designed for the majority, discriminate against minorities by failing to ensure that their special needs are recognised, understood and appropriately responded to.** The result is that public services may not benefit all citizens equally in the important areas of their social and health care. This is not just a question of communication, but addresses a wider issue of accessibility, cultural sensitiveness, service responsiveness and rights.

2. **There is under representation from those groups that are the subject of discrimination within the ranks of senior professionals and managers within the public administration of health and social services**. Whilst this is not a problem which is confined to health and social services or even just to the public sector; (there are similar low levels of representation in the private sector), it is nevertheless of serous concern that those managing diversity may not include staff from groups experiencing discrimination. This is not a symbolic issue but one of equal opportunity, which would also ensure public services benefit from the richness of the communities they serve.

3. **Whilst health and social services often serve the same population, their approaches to combating discrimination are not always shared with each other.** Consumers of both services risk having to overcome further barriers to accessibility and continuity of service due to lack of co-ordination between these services. This is all the more important and timely, for in many European countries, public health and social services are now developing joint commissioning and service strategies with shared budgets and staff.

Summary

1. Introduction

1.1 This report documents how EU member states tackle disability discrimination and promote disability equality in health and social service organisations. It explores the different ways in which health and social services across Europe are providing services in non-discriminatory ways. The report addresses the twin concerns of discrimination by and within public organisations on the basis that there is an important relationship between how an organisation treats its customers and how it treats its employees.

2. The experience of disability

2.1 Disabled people are experience high levels of exclusion and marginalisation in Europe. These can be seen from the low levels of participation in work and society. 17% of people in the EU have a chronic illness or disability; 15% of these are of working age. A recent study found that only 30.5 % of the disabled labour force population is employed. The rest is either unemployed (20.8%) or inactive (42%).

2.2 Problems related to mental health are increasing. In Europe about 25% of new disability benefits are due to mental health difficulties and this share is increasing. It is estimated that mental disorders will account for 22% of the total burden of disease in 2020. In the EU about 5% of the population suffer from depression but more than twice as many women suffer as men.

2.3 The non-participation of people with disabilities in the labour market is almost twice as high as non-disabled people. Many people who are not in paid work report that they could have remained in work if suitable adaptations had been offered. Non-participation in the labour market increases after the age of 50. This poses the general problem of older workers' participation and its link with health.

3. EU and international disability policy framework

3.1 European legal norms and measures are increasingly shaping the development of disability policies at the national level, both in terms of equality and diversity *within* and *by* the organisation. This has been reinforced by international developments at the level of the United Nations and the World Health Organisation; whilst at the European level these developments have been established by the Council of Europe and more recently the European Union. The recent Directive on Employment Equality and the possible development of a separate disability directive are part of this trend.

3.2 The Directive on establishing a general framework for equal treatment in employment and occupation on grounds including disability was adopted on 27 November 2000. It prohibits direct or indirect discrimination on several grounds, including disability.

4. Different models and approaches to disability in the EU

4.1 There is a wide diversity of models of health and social service provision in the Member States of the EU. Services are relatively well developed in the Nordic countries, where universal entitlements to services exist. In contrast, services remain rudimentary in Spain, Greece and Portugal, and to a lesser extent in Italy and Ireland, where public services sit alongside family and charity based systems of care.

4.2 There are also a variety of different models of health service financing. These include tax-based models, social insurance models, controlled market insurance and private insurance. The UK, Sweden and to a lesser extent Ireland fall within the tax based financing model, whereas Belgium, Germany, France and the Netherlands operate social insurance based funding mechanisms.

4.3 There has been a growth of civil rights and anti-discrimination laws and policies as part of a commitment to the promotion of equality and the prevention of discrimination in employment, goods and services. In some cases the legislation may guarantee rights to specific services although in others general principles may underpin equal participation through user-led approaches and a social model of disability. The UK Disability Discrimination Act and the American Disabilities Act are considered amongst some of the best examples in the world, both of which will shortly be amended to provide for a more enhanced rights-based approach.

4.4 At the national level there is a growing recognition of the importance of anti-discrimination legislation as part of the civil rights model. The emergence of disability rights and policies to promote equal opportunities have been related, on the one hand, to the development of civil rights for disabled people across Europe, and on the other, to the importance governments now attach to integrating disabled people into work and reducing welfare dependency

4.5 Different approaches to the rights of disabled people are in evidence. In the UK the approach is rooted in strong anti-discrimination legislation, whereas countries like Germany and Finland have a history of mainstreaming. In Germany, and Finland (and Canada) provision is made in constitutional law, whereas in Britain, Sweden and Ireland provision is made in civil law, and in France in criminal law. A particular role is played by human rights legislation in the UK (and outside of Europe in the USA, Canada, New Zealand and Australia). The EU Framework Directive on Anti-Discrimination, mentioned above, requires all EU member states to implement anti-discrimination legislation that make it unlawful for employers to discriminate on the basis of recruitment, promotion and terms and conditions of employment. In some countries there are employment supports available to employers so that they do not have to carry all the costs that are required to support a disabled person in the workplace.

4.6 Although a large number of countries have outlawed discrimination against disabled people in employment, this approach is more limited in the area of legally enforceable rights to health and social care services for people with disabilities. There are some rights based approaches to health and social welfare provision and some interesting examples of the right to certain services has been established in Sweden, Germany and Finland, a well as further afield in the USA, Australia and Canada.

4.7 In Sweden and Finland, there is a right to named services, including personal assistance and support. In Germany legislation introduced in 2002 on equality of

treatment (Behindertengleichstellungsgesetz, BGG) has the goal of eliminating discrimination of disabled people to ensure their participation in society, the elimination of barriers and the provision of sign language. The legislation contains a right to take legal action for associations/organisations of disabled people (who are significant service providers in Germany) if rights are violated, but not the right to action for individuals.

4.8 Several countries have agencies that are established to support the development of disability equality and the implementation of legislation, for example, the Disability Rights Commission in the UK, the Disability Ombudsman in Sweden, and the Equality Authority and National Disability Authority in Ireland.

5. Good practice in the provision of disability services

5.1 The report documents many good examples of ways in which health and social service organisations are improving the quality and accessibility of services for people with disabilities. The ESN survey found that many health and social service organisations have specific policies to meet the needs of disabled people, as well as mainstreaming disability through all service functions. This has included the development of quality standards in services.

5.2 Much good practice is rooted in a social model of disability. This stresses the need to remove barriers to participation and through this the promotion of independent living, personal assistance, civil rights for people with severe disabilities, community based services and community integration. In this context services should be provided, planned and monitored with the full participation of people with disabilities and their families.

5.3 The ESN survey found the following developments in disability services:

- Greater representation of people with disabilities on decision-making bodies and the involvement of disability service users in the planning, organisation and monitoring |of services

- Increasing targeting of health and social services for people with disabilities which has enabled a greater emphasis to be placed on the coordination of services and the development of multi-disciplinary teams and multi-dimensional policies.

- Service developments are increasingly located in community-based and interdisciplinary approaches with the full participation of disabled person and his/her family in decision-making.

5.4 The report documents the following good practice examples:

- The provision of services by people with disabilities for people with disabilities, for example, based on the Clubhouse model for people with mental health difficulties.

- Integrated approaches to health and social services for people with learning disabilities in Lanarkshire Council, Scotland

- Independent living and user-led initiatives that enable choice, control, autonomy and participation

- Assertive outreach which targets clients with severe and enduring mental health problems who have difficulties engaging in services, through multidisciplinary team approach, intensive frequency of client contact, work with people in their own environments and with their own support networks.

- Participation of service users in the planning, development and monitoring of services. The survey shows that health and social service organisations have been under significant pressure to involve service users more effectively.

- Evidence based service planning based on needs assessments and which can help to provide a baseline profile of health needs and an evidence base

for future service planning. The European Observatory on Health Care Systems supports and promotes evidence-based health policy-making.

- Improved data and information systems to identify needs, plan services and monitor change and ensure equity of service provision.

6. Disability equality within organizations

6.1 The low level of disabled people in the workforce is a consequence of a range of factors. The European Disability Federation state that the high rates of unemployment and inactivity of disabled people are a consequence of prejudice, lack of education and training, inaccessible workplaces, lack of support and low pay.

6.2 Health and social service organisations have been slow to address the needs of disabled staff and to encourage the higher participation of people with disabilities in their employment.

6.3 Unlike the previous ESN report on Race prepared for the Manchester Workshop, there appear to be fewer examples of initiatives to support and develop disabled staff, particularly into managerial and senior positions. Nevertheless, the diversity in the workforce in the public sector has become an increasingly important objective that is linked to two important goals notably the improvement of equity within organisations and improvements in services delivery.

6.4 Many governments, health and social service agencies are now implementing or considering plans for diversity in organisations by implementing greater workforce diversity for people with disabilities, and in some cases at managerial and senior levels. The objective is to match the public sector workforce to the customer base and the profile of the community at all levels. In some countries specific performance objectives have been developed and diversity management plans have been developed.

6.5 Integrating people with disabilities and mental health difficulties into mainstream employment has resulted in a shift of policy away from sheltered workshops to more active, coordinated and supported training and employment projects in most European countries.

6.6 There are a significant number of employment policies for disabled people many of which have been influenced by the EU's Employment Guidelines as well as national developments. These include special schemes to provide work experience, start-up grants to set up own business and self-employment, the adaptation of the work place, through grants for work adaptation and of technical aids, and personalised support with grants for a tutor, job coach or a personal assistant in the enterprise.

6.7 In practice very few health and social services organisations have disabled people in senior and managerial positions. The percentage of the workforce that is disabled is also relatively small. The ESN survey found that this ranged between 1% and 3% of the total workforce.

6.8 Disability issues have been raised in the EU National Action Plans on Employment. Since 1998, the Employment Guidelines and the associated

National Action Plans for employment have stressed the important of removing barriers to enable disabled people to enter and be retained employment. Particular importance has been given to removing barrier to full participation in working life and to developing policies that combat discrimination and promote the integration of disabled people into work.

6.9 A number of countries have introduced job creation programmes and special supports, incentives or subsidies for the employment of disabled. In addition, there are also duties and requirements on public bodies in a large number of countries to employ disabled people through quotas.

6.10 Most EU member states and Norway have legislation concerning discrimination on the grounds of disability and/or specific laws, which regulate various aspects of the employment of people with disabilities. Discrimination at work on the grounds of disability is prohibited by the constitutions of Finland, Greece, Italy, Portugal and Spain. Specific laws forbid such discrimination either as part of general anti-discrimination legislation (Denmark and Ireland), or through specific legislation (France, Spain, Sweden and the UK). Several countries have specific laws which contain various measures related to the occupational integration of disabled people, most notably addressing the issues of employment quotas, protection against dismissal and, to a lesser extent, regulation of pay.

6.11 A greater emphasis is now being given to managing disability at work as a means to improve the quality of the workforce and its ability to deliver to customers in effective ways. The ILO Code of Practice on Managing Disability in the Workplace is an example of the importance now attached to managing disability.

6.12 There is a need to develop a more strategic approach and build best practice, foster leadership and cultural change, improve community engagement and support progress.

6.13 Equal opportunities monitoring has become an important to the overall achievement of equality in the workplace. This means going beyond the collection and analysis of data to assessing the effectiveness of an organisation's policies, processes and practices. It can help to provide a picture of the composition of the workforce, where particular groups are under-represented and help organisations to make the best use of their staff.

6.14 The ESN survey found evidence of policies to support the employment and career development of disabled people in health and social service organisations. However, these policies rarely seem to translate into practice given the continuing low level of employment of disabled people in senior and managerial positions in health and social services organisations.

7. Suggestions for improvement actions

7.1 A key role for the future of health and social care services is to ensure that there is integration and coordination with the full range of services that are essential for participation in society.

7.2 An important issue is the development of more effective evaluation and information systems so that service needs can be identified and translated into service planning and workforce planning.

7.3 Providing for more diverse workplaces and more accessible and user focussed services means exploring how barriers to participation can be overcome and how quality improvements can lead to real improvements in both the employment of people with disabilities and in improving access to services.

7.4 An important issue is the development of more effective evaluation and information systems so that service needs can be identified and translated into service planning and workforce planning. This is essential to the provision of quality services that map services as they develop and measures issues such as equity of service provision, local needs assessment, service and workforce planning.

7.5 In the area of managing diversity within the organisation there are a number of key issues to address in order to rectify the low level of employment of disabled people in health and social service organisations, particularly at senior levels. This means making sure that organisations are more accommodating of equality and diversity, including the development, assessment and implementation of policies relating to staff with disabilities within a broad diversity framework.

7.6 There is also a need for better knowledge and awareness about the benefits of valuing and accommodating diversity in the area of disability so that disability issues can be mainstreamed throughout all areas of the organisation and championed at senior levels.

7.7 Similarly there is a need to establish fora for employees with disabilities for the exchange of ideas, good practices and for support. There is a need for policies and mechanisms to support and develop staff. Finally, raising the awareness of everyone in the organisation will be important to promoting a culture that accommodates and promotes diversity.

1. Introduction

This report documents a number of different approaches to tackling disability discrimination and promoting disability equality in health and social service organisations. It is based on a survey of ESN member organisations[1] as well as additional desk research to identify national and local policies and initiatives. The report will contribute to a final report to be produced by the ESN that will cover the three grounds of Race, disability and age.

The provision of health and social services across Europe in non-discriminatory ways has led to a range of initiatives that accommodate diversity in an environment of equality of opportunity and equality of participation in society. This means that services have to reflect diversity and take on board issues such as access, unequal participation and discrimination. For this reason the report addresses the twin concerns of discrimination by and within public organisations on the basis that there is an important relationship between how an organisation treats its customers and how it treats its employees. Disabled people are experience high levels of exclusion and marginalisation in Europe. These can be seen from the low levels of participation in work and society.

Health and social care services are increasingly being provided within a social model of disability. However, support services are often controlled and allocated by health service professionals and with limited participation of disabled service users. In many cases health personnel lack expertise in the provision of general health care for people with disabilities, health information and health advice is often limited and negative assumption are commonplace. The low priority given to health and social services is exacerbated by the fact that medical services are orientated to prevention and acute treatments rather than long-term supports, particularly for mental health system users. Moreover, medical services do not empower people to live independently in the community and the shift to a social model of disability has been hindered by a historical and institutional reliance on a medical and welfare model of disability. This is made worse by the fact that services are poorly coordinated and integrated which in turn has a major impact on the planning of quality health and social care services.

Nevertheless, positive developments in the provision of health services for people with disabilities can be found in most European countries, for example, there is increasing provision of services by people with disabilities for people with disabilities, for example, based on the Clubhouse model for people with mental health difficulties. Similarly, there is also a greater representation of people with disabilities on decision-making bodies and the involvement of disability service users in the planning, organisation and monitoring of services. Also the growth of more targeted health services for people with disabilities has enabled a greater emphasis on the coordination of services and the development of multi-disciplinary teams.

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[1] The survey was based on a detailed questionnaire and a short questionnaire sent to health and social service organisations who are members of the ESN. There was a poor response to the questionnaire and it is hoped that more responses to the questionnaires can be sought and a larger number of examples of practices documented after the ESN's workshop in Gothenburg. The final report will also draw on the two focus groups being held in Ireland and Sweden and on discussion at the Gothenburg workshop.

The Social Model of Disability

International best practice shows the need for services should be provided within a framework of the social model of disability. Whilst medical services may be necessary for people with disabilities, support, assistance and care does not need to be and should not be organised around a medical model. The increasing focus on rights-based approaches and the emphasis on legal protections are an important part of this broader framework. Social care services can help to support the integration and participation of disabled people by providing support that promotes independence, social inclusion, choice and control for all disabled people.

The social model of disability is designed to remove barriers to participation, including policies to support independent living, personal assistance, direct payments and personal budgets, civil rights for people with severe disabilities, community based services and community integration. Services should be user-led and provided, planned and monitored with the full participation of people with disabilities and their families. It follows that community-based services, which are also led (and sometimes provided by disabled people) within a social model place an emphasis on the disabling environment rather than on the disability. The growth of the independent living movement Sweden and the UK, the provision of direct payments and Centres for Independent Living have enabled independence rather than dependence on disability supports.

The interest in rights-based approaches in legislation, giving access to legally enforceable rights to services and to non-discrimination, has been an important part of the development in thinking in most European countries. Much of this has been inspired by the American With Disabilities Act and the UN Standard Rules and is part of the broad development of a European model of social rights, social cohesion and social inclusion. Degener and Quinn (2000) argue that the paradigm shift from the medical to the social model of disability has enabled disability to be seen as a human rights issue.

This shift in thinking about disability and changing attitudes to people with disabilities has resulted a policy focus on inclusion, rights and independence. This has required the development of new skills and services that are community-based and geared to service users own needs and aspirations, and that are user-led. This contrasts sharply with care services that are deliverer-led resulting in services being determined by the service provider who assesses the needs of the disabled person and then decides which services can be provided. These issues regarding the provision of services for and by disabled people have important implications for the development of diversity with organisations, and in particular the role of disabled people at all levels of the organisation.

Disability and the experience of discrimination and exclusion: some facts and figures

Research by the European Foundation found that in the EU the following percentage of people with a chronic illness or disability is as follows:

- people with a chronic illness or disability: 17%;
- working-age population with a chronic illness or disability: 15%;
- people with a work-limiting illness or disability is about 12%;
- working-age population with a significant chronic illness or disability: 8% - 10%;
- working-age population receiving a disability-related benefit: 6%.

Member States impose minimum conditions for the degree, the duration and the nature of an illness or disability. So the number of people receiving a benefit related to chronic illness or disability is around 6% of the working-age population. Eligibility and levels of assistance vary from one member state to another.

Problems related to mental health are increasing. In Europe about 25% of new disability benefits are due to mental conditions and this share is increasing. It is estimated that mental disorders will account for 22% of the total burden of disease in 2020. In the EU about 5% of the population suffer from depression but more than twice as many women suffer as men.

The unemployment rate of people with a moderate illness or disability is about twice the level of those with no disability, while the unemployment rate of people with a severe illness or disability is about three times the level of the non-disabled. The non-participation of people with disabilities in the labour market is almost twice as high as non-disabled people. Many people who are not in paid work report that they could have remained in work if suitable adaptations had been offered. Non-participation in the labour market increases after the age of 50. This poses the general problem of older workers' participation and its link with health. The employment rate of women with disabilities compared with that of non-disabled women varies sharply between countries, revealing a significant disadvantage for women with disabilities in some countries.

A 1995 Eurostat study showed that the proportion of disabled people compared to the total population was around 12%, with differences among member states from 9.3% in Greece to 15.2% in Spain. The 2001 publication by Eurostat, based on the findings of the European Community Household Panel found similar results. The findings of the ECHP study highlight the demographic and socio-economic differences related to disabled persons in selected EU countries. The results reveal that around 13% of the EU population is being severely hampered (4%), or hampered to some extent (9%). The significant disparities in the education and employment status in the member states is related to different policies and labour market structures. Some countries, notably Finland, France and Austria, have achieved high rates of employment for their population whereas countries like Greece and Spain with relatively lower levels of participation rates and more limited opportunities to disabled people to access the labour market.

ATTITUDES OF EUROPEANS TOWARDS DISABILITY

Results from Eurobarometer 54.2 (based on a survey of 16,000 people)

a) Close to six Europeans out of ten know someone, in close or more distant circles, who is affected by a long lasting illness, disability or invalidity. More than 5% of EU citizens consider themselves as a disabled person.

b) 76% of EU15 respondents think that the access for blind people to basic public equipment and events is difficult. 73% believe that it is too difficult for intellectually disabled people, 71% for the physically disabled, and 54% for deaf people. However, 57% of respondents consider that the access to public spaces for people with disabilities has been improving in the course of the last 10 years.

c) 66% of EU15 respondents consider that local authorities are the ones truly responsible for improving access to public spaces for people with disabilities. 55% think that it is the government, 30% employers and companies and 28% voluntary or charitable organisations. The European Union comes in 5th position with 16%.

d) From a list of 21 types of disabilities, 57% of the EU15 respondents admit to a lack of knowledge. Only 4 types of disabilities have achieved a level of knowledge of at least 50%. In descending order these are cancer (61%), asthma and diabetes (58%) and arthritis (54%). Nearly one out of four Europeans thinks that 20% or more of their country's population have a physical disability of some kind.

e) 97% of EU15 respondents think that something should be done to ensure a better integration of people with disabilities into society. 93% express the desire to dedicate more money to the removal of physical barriers that complicate the life of people with disabilities.

2. European Union and other international instruments on disability

European legal norms and measures are increasingly shaping the development of disability policies at the national level, both in terms of equality and diversity *within* and *by* the organisation. This has been reinforced by international developments at the level of the United Nations and the World Health Organisation; whilst at the European level these developments have been established by the Council of Europe and more recently the European Union.

European Union policy

Good practice being established at the European level in a variety of ways to promote equality and the European social model. A key shift in European policy has been to develop new anti-discrimination measures and mechanisms for the exchange of good practice through the open method of coordination in European policy established at the Lisbon Council in 2000. The European Year of People with Disabilities, 2003, has also helped to focus minds on disability discrimination and awareness about the ways in which barrier to full participation can be eliminated. The European mechanisms include:

Treaty on European Union and Anti-Discrimination
In the area of anti-discrimination Article 13 of the Treaty on European Union explicitly refers to disability discrimination. This has led to the introduction of a new generation of directives focussed on anti-discrimination. The bulk of these legal provisions, however, concern employment opportunities and non-discrimination in access to employment and training. Issues concerning health and social care, for reasons of subsidiarity, remain the competence of the member states.

The Directive on establishing a general framework for equal treatment in employment and occupation on grounds including disability was adopted on 27 November 2000. It prohibits direct or indirect discrimination on several grounds, including disability. The prohibition of discrimination applies to:

- conditions for access to employment, to self-employment or to occupation, including selection criteria and recruitment conditions, whatever the branch of activity and at all levels of the professional hierarchy, including promotion;
- access to all types and to all levels of vocational guidance, vocational training, advanced vocational training and retraining, including practical work experience;
- employment and working conditions, including dismissals and pay;
- membership of, and involvement in, an organisation of workers or employers, or any organisation whose members carry on a particular profession, including the benefits provided for by such organisations.

The Directive will provide important protection against discrimination in the field of employment and training for 37 million disabled citizens in the European Union.

Disability and social exclusion

Disability is also an important theme related to EU policies to combat social exclusion. The agreement at the Nice European Council for a new impetus for the development of actions to combat poverty and social exclusion have resulted in an open method of policy coordination, national action plans on social inclusion, and an action programme designed to strengthen member states efforts in developing indicators, benchmarking, improved statistical information, research, networking and exchanging of good practice.

In 2001 the Employment and Social Affairs Council reached political agreement on the setting of quantitative objectives on fight against social exclusion and poverty. The implementation of this is part of the coordinated approach decided at the Lisbon Council, the open method of coordination, where the EU member states define joint objectives to be translated in national action plans. The first plans were produced in 2001 and the second plans were produced in 2003. The objectives are set around four main themes: a) to promote participation to employment and universal access to resources, rights, goods and services, b) prevent risks of exclusion, c) action for the most vulnerable persons, and d) mobilise all the relevant actors. These objectives recognise the multiple dimension of exclusion and the need for action in employment, education, vocational training, health and housing policies and for specific target groups. Disability is referred to as a major factor leading to exclusion and poverty.

Resolution on employment and social integration of people with disabilities

The Ministers of Employment and social affairs have adopted a resolution on employment and social integration of people with disabilities. Particular attention has been given to their integration into the mainstream labour market. The resolution also contains a reference to the UN convention on the rights of people with disabilities. Member states are asked to:

- implement within the deadlines the framework directive on equal treatment in employment;
- consider the possibility to take measures both at the national and European level on the employment of people with disabilities;
- mainstream disability issues when drafting future national action plans on social exclusion
- to collect statistical material on the situation of people with disabilities broken down by gender including information on services and benefits

Charter on Fundamental Rights

An emphasis on the social model of disability can be seen in recent policy statements and the Charter of Fundamental Rights agreed at the Nice Summit in December

2000. The Charter recognises the importance of the prohibition of discrimination and the right of people with disabilities "to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community" (Article 21)

Community Action Programme to Combat Discrimination

The Community Action Programme to Combat Discrimination (2001-2006) aims to support member states in developing legislation and policies for combating discrimination. It covers a seven grounds of discrimination. The programme aims to strengthen the capacity to address or prevent discrimination through exchanges of information and good practice, and through awareness raising. Anti-discrimination measures are further developed under the *Social Policy Agenda* and through the inclusion of provisions for the respect for fundamental social rights 'as key components of an equitable society and of respect of human dignity' (European Commission, 2000:22). This project run by the European Social Network is one initiative funded under this programme and is helping to establish good practices across Europe in relation to health and social care services for people with disabilities, minority ethnic groups and older people.

Other initiatives

- Since 2001 the Employment Guidelines and National Action Plans have included action for disadvantaged groups and action to combat discrimination in access to employment, including disability.

- The EU EQUAL initiative, funded under the European Social Fund, is testing and promoting new methods of combating all forms of discrimination and inequality in the labour market for those in and out of work. It is based on the principles of innovation, a thematic approach, transnationality, equal opportunities, mainstreaming and empowerment. Funds are channelled through Development Partnerships, which encourage participation and transnational exchanges.

- The programme of transnational measures as part of additional funding allocated for *European Year of People with Disabilities* (including a €12m budget for national and transnational meetings, events, information, surveys and studies).

- The EU has the competence to increase its role in the promotion of good mental health through prevention-orientated initiatives as part of the obligations on public health in the Treaty on European Union.

- The importance attached to disability issues at the EU level can also be seen in a number of declarations and agreements at the EU level, for example, the ETUC/EDF Social Partner Agreement on Disability. **See Appendix 1 for the text of the Agreement: *Declaration of the social partners on the employment of people with disabilities.***

- The development of the organisation of people with disabilities and disability organisations at the European level has been a reflection of the importance attached to these issues to lobbying for European policies. A document of major importance to the development of disability services has been the Madrid Declaration of the European Disability Forum. This a vision developed at the European Congress on Disability welcoming the proclamation of 2003 as European Year of People with Disabilities. The Declaration sets out a framework for action at European Community level, national, regional and local level. Various actions are suggested for the EU, local authorities, disability organisations, employers, trade unions, media, education institutions, disabled

people to implement. The preamble to the Declaration states that disability is a human rights issue, based on equal opportunities not charity, and removing barriers in society that lead to discrimination and social exclusion. The Programme for Action includes covers legal measures and anti-discrimination, changing attitudes, independent living, support to families, special attention to disabled women, mainstreaming disability, employment and participation of people with disabilities. **The full text of the Madrid Declaration can be found in Appendix 2.**

Other international instruments impacting on disability rights

In addition there is an important body of policies in the area of civil, political, social and economic rights emanating from the Council of Europe and the United Nations that have had a considerable impact on rights for disabled people.

The Council of Europe[2] has been important in establishing a range of civil, political, social and economic rights in the European region. The implementation of human rights legislation in the UK and Ireland and the incorporation of the European Convention on Human Rights and Fundamental Freedoms into European Union law has the potential to impact directly and significantly on the human rights of people with disabilities. For example, in the UK the Human Rights Act has particular relevance in that people with disabilities can litigate against the withdrawl or restriction of medical services and the abuse and degrading treatment of disabled people in institutional care.

At the international level policy is reinforces and establishes good practice at the national level. Disability is now part of the mainstream international human rights agenda. In 1985 the Universal Declaration of Human rights was extended to include disabled people and in 1993 the UN *Rules on the Equalization of Opportunities for Disabled Persons* addressed participation in eight specific areas: accessibility, education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion. Although not legally binding, the Standard Rules represent a strong moral and political commitment by Governments to take action for the equalisation of opportunities for people with disabilities. The rules serve as an instrument for policy-making and as a basis for technical and economic cooperation. The Standard Rules consists of 22 rules summarising the message of the UN. The 22 rules cover four chapters - preconditions for equal participation, target areas for equal participation, implementation measures, and the monitoring mechanism - and cover all aspects of life of disabled persons. According to Degener and Quinn (2000) there is "No doubt the UN Standard Rules of 1993 provided the key moral imperative for change on a worldwide basis." Rule 15 of the Standard Rules sates that "States have a responsibility to create the legal basis for measures to achieve the objectives of full participation and equality for persons with disabilities". Currently, there is growing support for the introduction of a UN Charter for People with Disabilities along the lines of those already developed for women and minority ethnic groups.

The World Health Organisation (WHO) has also established a classification for the functioning, health and disability of people. The ICF (International Classification of Functioning, Disability and Health) was established in order to focus attention on quality of life, health and social policies to improve access and treatment, and take

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[2] The Council of Europe was established in 1949 to protect human rights and has 41 member countries

account of social aspects of disability by focussing on the impact of the social and physical environment on a persons functioning. Initiatives in the WHO impacting on the development of good practice at the national level include the 2001 campaign on mental health, and annual report 2001 focused on "*Mental Health: New Understanding, New Hope"*, includes recommendations about what states should do to improve mental health care.

3. Health and social services at the national level

This section explores health and social care service provision for people with disabilities as well as disability rights. It begins with a discussion of health care funding and the organisation of services. There is now more evidence of coordinated services through multidisciplinary approaches to providing services for people with disabilities in recognition of the both a social model of disability and the multi-faceted problems and needs that extend beyond health and social services to housing, transport, training, employment and so on. Alongside the increasing emphasis given to the participation of services users there is now a much a greater understanding of the service needs of users across Europe.

The organisation of health and social services in Europe

There is a wide diversity of models of health and social service provision in the Member States of the EU. Services are relatively well developed in the Nordic countries, where universal entitlements to services exist. In contrast, services remain rudimentary in Spain, Greece and Portugal, and to a lesser extent in Italy and Ireland, where public services sit alongside and fund family and charity based systems of care.

There are also a variety of different models of health service financing. These include tax based models, social insurance models, controlled market insurance and private insurance. The UK, Sweden and to a lesser extent Ireland fall within the tax based financing model, whereas Belgium, Germany, France and the Netherlands operate social insurance based funding mechanisms. The structure, funding and organisation of the health and social care services vary significantly across the EU. In summary, four main welfare regimes exist in Europe (Pillinger, 2001, Esping-Andersen, 1990).

- *Continental Europe (Germany, France, Belgium, Austria, the Netherlands and Luxembourg).* The provision of insurance-related social benefits outweighs the provision of services. This model has particularly facilitated direct payments for people with disabilities. Health care is financed from social insurance.

- *Social democratic model or Scandinavian model.* Universal services and the entry of women into the labour market became the mechanism for fulfilling social needs, financed through direct taxation. The model is based on principles of social rights derived from citizenship, universalism, redistribution, social partnership and a strong public sector.

- *The UK and Ireland.* A model of welfare rooted in the Beveridge principles of universalism, although benefits are at lower levels and have a higher degree of selectivity than in the social democratic model. In the UK health care is funded through national taxation, whereas in Ireland there is a unique mix of national taxation and private insurance. In Ireland charitable organisations and the church play an important role in service delivery

- *Southern Europe.* Portugal, Spain, Italy and Greece have developed rudimentary welfare systems based largely on family and voluntary systems of support and limited state involvement. Health services are funded by insurance.

Equality, rights to services and legal protection against discrimination

The role of civil rights and enforceable anti-discrimination laws and policies is part of a commitment to the promotion of equality and the prevention of discrimination in employment, goods and services. In some cases the legislation may guarantee rights to specific services although in others general principles may underpin equal participation through user-led approaches and a social model of disability. Although legislation varies from country to country this is part of good practice in the development of equality and access to services. The UK Disability Discrimination Act and the American Disabilities Act are considered as some of the best examples in the world, both of which will shortly be amended to provide for a more enhanced rights-based approach.

At the national level there is a growing recognition of the importance of anti-discrimination legislation as part of the civil rights model. However, this approach sits alongside more traditional approaches to disability policy at the national level which tend to operate within a medical model and sit alongside long-established social security schemes, segregated education and housing programs, and employment quotas, many of which exist within a social welfare model. This tension suggests the need to consider disability policy with a new framework of a social model and requires fundamental re-thinking of the existing organisation, funding and provision of health and social care services.

According to Degener and Quinn (2001) most countries are beginning to view disability as a human rights issue. The emergence of disability rights and policies to promote equal opportunities have been related, on the one hand, to the development of civil rights for disabled people across Europe, and on the other, to the importance governments now attach to integrating disabled people into work and reducing welfare dependency. In mental health care models have shifted from health care into social support, education and work-related activity. These developments are rooted in user empowerment, new ethics of care based on empowerment, and principles of independent living. These have challenged professional attitudes and services that are disabling" (Pillinger, 2001).

Different approaches to the rights of disabled people are in evidence. In the UK the approach is rooted in strong anti-discrimination legislation, whereas countries like Germany and Finland have a history of mainstreaming. In Germany, and Finland (and Canada) provision is made in constitutional law, whereas in Britain, Sweden and Ireland provision is made in civil law, and in France in criminal law. A particular role is played by human rights legislation in the UK (and outside of Europe in the USA, Canada, New Zealand and Australia). As a result of the EU Framework Directive on Anti-Discrimination mentioned above all EU member states are required to implement anti-discrimination legislation that make it unlawful for employers to discriminate on the basis of recruitment, promotion and terms and conditions of employment. In some countries there are employment supports available to employers so that they do not have to carry all the costs that are required to support a disabled person in the workplace

A large number of countries have outlawed discrimination against disabled people in employment, this approach is more limited in the area of legally enforceable rights to health and social care services for people with disabilities. There are some rights based approaches to health and social welfare provision and some interesting examples of the right to certain services has been established in Sweden, Germany and Finland, a well as further afield in the USA, Australia and Canada.

In Sweden and Finland, there is a right to named services, including personal assistance and support. In Germany legislation introduced in 2002 on equality of treatment (Behindertengleichstellungsgesetz, BGG) has the goal of eliminating discrimination of disabled people to ensure their participation in society, the elimination of barriers and the provision of sign language. The legislation contains a right to take legal action for associations/organisations of disabled people (who are significant service providers in Germany) if rights are violated, but not the right to action for individuals.

The rest of this section provides an outline of disability policies and legislation in selected countries that represent best practice models: Denmark, Finland, France Ireland, the Netherlands, Sweden and the UK.

Appendix 4 give a brief summary of the organisation of health and social services in each member state of the EU.

Disability policies in selected countries: Denmark, Finland, France, Ireland, the Netherlands, Sweden and the UK

Denmark

Denmark has a long tradition of social and rights based approaches that include the rights of people with disabilities to participate fully in public life. Denmark has a highly devolved system of social provision and resources are provided a local levels for this. A universalistic social democratic model that is primarily public sector led and provided, and funded through taxation. It is based on principles of universalism, equality and redistribution. This model has been open to criticism and scrutiny in recent years for its financial burden, inefficiency and paternalism. There are increasing problems of waiting lists, concerns about a growing number of unsupported vulnerable groups, concerns about the legitimacy of the model, and a breaking of the consensus over the welfare model that has dominated the post-war Danish welfare system. In contrast to other Scandinavian countries the Danish model places a higher priority on social services than on social security benefits. The majority of services are provided at the local level (social services) or the regional level (health).

The Danish health care system provides a range of prevention, early detection, diagnosis, rehabilitation and treatment programmes for people with disabilities within the general medical system. People with disabilities and their families are sometimes involved in the planning and monitoring of services. Medical care is provided free of charge through the Danish social insurance system. Health services as provided at local, district, provincial and national levels. A national programme of rehabilitation is provided through community based programmes provided by local, district and county governments. People with disabilities are also involved in the design and provision of rehabilitation programmes. Support services are provided by local municipalities and personal assistance is provided at home, school, work, and leisure. Interpreter services (provided through sign language and speech interpretation) are provided at home, school, work, leisure and at health and social service provision is provide free of charge by the municipalities.

Disability issues are included in the training of professionals and staff training programmes are developed in consultation with people with disabilities and directly involve people with disabilities as teachers, instructors and advisors.

In 1993 the Danish parliament adopted "*B 43, Folketingsbeslutning om ligestilling og ligebehandling af handicappede med andre borgere*" (parliamentary resolution

concerning equalisation of opportunities for disabled people and non-disabled people). The resolution states that Danish disability policy rests on a principle of equal opportunities for disabled citizens and non-disabled citizens. The resolution states that: "The Danish parliament appeals to all national and municipal authorities as well as private enterprises that, with or without public support, they: follow the principle of equal rights and equality of opportunities for disabled persons compared with other citizens, and show regard for and create possibilities for expedient solutions in consideration of disabled citizens' needs in connection with the preparation of resolutions in which such consideration is at all relevant."

Denmark has also incorporated the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities. The parliamentary resolution is not a legally binding act but a decision in principle by which the Danish parliament signals that disabled persons should be given equal rights and be treated in the same way as non-disabled people. The primary objective of the parliamentary resolution is to promote a move in this direction.

Finland

Finnish health and social care services are based on a Nordic model of welfare with roots in Protestantism and democracy and a political tradition of social democracy. This has emphasised the role of the state in providing universal services and a basic minimum income for all. The main features of the Finnish model are comprehensive policies, social rights derived from citizenship, the public sector as the main provider, earnings-related and flat-rate income benefits, public provision of services financed by taxation, equality, and the redistribution of income. In recent years there has been the introduction of income-related charges and eligibility conditions for some services. Health and social services are decentralised to Finnish municipalities.

Since the 1970s there has been a policy shift away from institutional to open care for adults with learning disabilities and mental illnesses. This led to the introduction of a five-year plan, instigated by the National Board of Social Welfare, to develop community care services and make home care services compatible with other services. As a result the 1984 Social Welfare Act required municipalities to develop services for adults with learning disabilities that are generally available to other municipal residents. In practice, the bulk of care is provided at home by families, and as a result the introduction of home-care services has been highly important in enabling this target group with learning disabilities to be cared for in their own family settings.

Although the organisation and provision of care services vary across the Finnish municipalities regarding the organisation and provision of services, and there is evidence of improvements in services, resulting from increasingly effective collaboration between localities and different administrations, and better information about services. This is particularly the case where specialist services are required, and collaboration has been introduced for the purchase of these services from specialist care circuits. For instance, in the Padasjoki municipality, the provision of services for adults with learning disabilities among general municipal services, and the integration of services for disabled people with other welfare services, are considered to be positive developments by relatives and personnel. The coordination and integration of services for people with learning disabilities and people with mental illnesses has become more necessary in the light of these principles.

In Finland health care is provided at the local municipal, district level, provincial, and national levels and people with disabilities are included as part of the general medical

system. This includes general practitioner, specialised doctors, paediatrician, nurse, psychologist, primary health care worker, physiotherapist, speech therapist and occupational therapist. A primary health care model enables services to be provided in rural areas. Medical care is provided free of charge through the government's social insurance scheme. The health care system provides for a range of prevention, early detection, diagnosis and treatments; in some cases people with disabilities are involved in the planning and evaluation of services. A national rehabilitation programme exists and programmes are provided at local, district, provincial and national levels. Social care and home-based supports are provided by municipalities. This includes personal assistance, assistive devises and interpreter services.

A number of principles that have been developed in Finland as a basis for organising services for adults with learning disabilities. These include recognition for the person's potential to participate as an equal member of the community and society; normality and integration; integration and client-orientation; thinking in terms of life as a whole; quality of life and the right to self-determination.

The *Act on Services and Assistance for Disabled People* promotes independent living and equal opportunities and provides for services to be provided irrespective of financial or social status. The Act of 1987 provides as an individual right to independent living services for severely disabled people, such as transportation, housing, interpretation services and to personal assistance services. Because the Act's main purpose is to enable disabled persons to live as a member of society on equal footing with others the act is also called the *Disabled Person's Equality Act.* Of interest is that the Act suggests that inequalities can result from the provision or non-provision of services, for example services which are dependent on municipal funds. The *Act on the Status and Rights of Patients of 1992* has a clear anti-discrimination clause in relation to health care. Furthermore, the Finnish Constitution has been amended to include social and economic rights alongside traditional political and civil rights. This requires equal opportunities to be applied in all areas, including health, housing and education on the basis that "everyone who is incapable of securing the necessities of life with human dignity ha the right to the necessary income and care". A new provision includes the rights of people using sign language and the need for interpretation and translations services, the rights to which are now guaranteed in the law

Finland was the first country to adopt the UN Standard Rules in 1993, resulting in a disability policy programme in 1995. In 1995 the Constitution Act of Finland was amended to include the equal treatment of people with disabilities. A Toolkit has been developed by the Finnish government providing guidance to local authorities on how they can implement the Standard Rules at the local level.

France

The French model is based on two principles: insurance and assistance. Health and social care services are provided through a complex structure of state provision with a large number of services decentralised to local authorities, departmental authorities, and social and socio-medical institutions. The operation of assistance and insurance has led to problems with a dual system where responsibilities are divided between the government, regional and local authorities. An increasing number of services are now delegated by the government to the private sector and non-profit associations. The French Government is responsible for the approval and regulation of these organisations.

The French health care system operates at local, regional and national levels and is funded through a social insurance system which provides free health care. People with disabilities are treated as part of the general medical system, which provides for a range of prevention, early detection, diagnosis, treatment and rehabilitation services. A national rehabilitation programme exists and community based rehabilitation services are provided by NGOs. Support services are provided by local municipalities which are part funded by social insurance, local municipalities and NGOs. A range of personal assistance and interpreter services are provided. People with disabilities tend not to be involved in the planning and monitoring of services. In France recent reforms are marked by a shift from models of care assistance to models of support and the development of autonomy, self decision-making, independent living and integration into the labour market. In particular, education for young handicapped adults outside of the family has been developed in order to facilitate their integration into society, their autonomy and independence.

The French Penal Code makes it unlawful to discriminate against a person with a disability on the grounds of health or impairment when providing goods, services or employment.

Ireland

The disability policy in relation to health and social services include the provision of mainstream services as well as specifically targeted services for people with disabilities. People with disabilities are also included as one of the nine grounds in the Irish equality legislation (Employment Equality Act, 1998 and the Equal Status Act, 2000). Services for disabled people have been at a low level, with low levels of resources and unequal geographic coverage of resources and services. In recent years there has been a major push to improve both the quality and accessibility of services for disabled people.

A Strategy for Equality, the report of the Commission on the Status of People with Disabilities (1996), highlighted the needs and rights of people with disabilities to co-exist in a framework of independence and support. The report highlighted a number of problems and made recommendations for services to be developed within a social model of disability and for rights based legislation. The Commission's recommendations included the establishment of the National Disability Authority to oversee the implementation of new legislation for people with disabilities and a Disability Support Service providing advice, advocacy and support. In the review of progress in implementing the recommendations the following issues were highlighted as needing attention in health and social services:

- Accessibility of hospitals and other setting
- Liaison between hospital and community services for children with disabilities
- Disability awareness training for staff, research on technical aids and equipment
- Expansion of the home help scheme and respite care services
- Personal assistance services and peer support for deaf people
- Additional funding for services for people with disabilities
- Special units for continuing therapeutic care
- National standards for services for people with disabilities in the community
- Rights of patients and patient advocacy
- The need for health boards to review services with regard to equity, accountability and quality of services.

A key development has been the *Mental Health Act 2001* which covers a range of issues regarding the detention of psychiatric inpatients and inspection of approved centres. Most significant is the establishment of the Mental Health Commission and an Inspector of Mental Health Hospitals. The *National Disability Authority Act, 1999, e*stablished the National Disability Authority with responsibility for coordinating and developing policies for people with disabilities and advising the Minister of developments in disability policy and practice. The NDA is responsible for the development of standards for programmes or services provided for people with disabilities, act as an advisory body for the development of general and specific standards, and monitor the implementation of standards. It also has responsibility for the preparation of codes of practice and a disability equality awards system.

In 2001 the health strategy *Quality and Fairness – A System for You* was launched The principles of the policy are particularly relevant to people with disabilities and are important to underpinning the setting of standards in health care:

* Equity (people treated fairly according to need and targeting of health inequalities);
* People centeredness (a health system that identifies and responds to the needs of individuals, with co-ordinated planning and delivery, and participation of individuals in decision-making to improve their health);
* Quality (through the creation of evidence based standards set in partnership with consumers and externally validated; and the valuing of continuous improvement);
* Accountability (financial, professional and organisational accountability for better quality, efficient and effective health services). The goals outlined are equally relevant to people with disabilities and include better health for everyone, fair access, responsive and appropriate care, and high performance.

A number of specific policy and service developments for people with disabilities include the development of the Intellectual Disability Database and the Physical and Sensory Disability Database to assist with service planning, the injection of additional funding to increase service provision, strategies to develop services for people with mental health difficulties, physical and sensory disabilities and intellectual disabilities. In 2003 it is anticipated that new legislation, guaranteeing rights to disability support services in the areas of health and social services, independent advocacy and needs assessment, mainstreaming of disability, accessibility of public buildings and duties on public bodies to deliver on disability equality, will be agreed. This comes as a result of the failure of a previous piece of legislation to be enacted because of significant lobbying from the disability movement in Ireland.

Disability also sits within an equality policy context. The Equal Status Act prohibits discrimination in the area of goods and services on nine grounds (gender, marital status, family status, sexual orientation, religious belief, age, disability, race, membership of the Traveller community). Government services, including those provided by health boards, are covered under the Act although certain exemptions apply. The Act also covers disability access and requires an employer, a person providing goods or services, accommodation, educational institutions and clubs to do all that is reasonable to accommodate the needs of an employee or a person with a disability by providing special facilities or treatment. They are not obliged to do this is if the special facilities or treatment involves more than the nominal cost. The Act allows for positive action to promote equality of opportunity for disadvantaged persons and to cater for the special needs of persons or a category of persons who may require facilities, services or assistance. The Employment Equality Act covers the same nine grounds in relation to employment. It covers part-time and full-time workers and includes access to employment, conditions of employment, training,

promotion and dismissal in the public and private sectors. The new equality directives from the European Union will further impact on equality.

The Netherlands

The Netherlands is characterised by a social democratic model with high levels of welfare spending and access to universal and comprehensive benefits, although influenced by Christian Democratic ideology and a social insurance model. The social partnership model between government and interest groups have introduced wage moderation, control of public spending and control on social security has had some successes. This led to an agreement to trade off wage moderation for an increase in jobs between the social partners, a reform of the social security system, including cost containment, cuts and measures to reintegrate people into work. The 'polder model' also led to new systems of consultation, discussion and consensus building activities that were also applied to the health service through systems of self-administration at local levels, alongside the introduction of marketisation of services. The Netherlands has highly decentralised services and a high level of provision and its services are universal. The bulk of services are provided by non-profit organisations that are funded by the state, local authorities and social insurance. These organisations have moved from being charities to professional service providers. The emphasis is on public funding and private provision of care and the development of a market-orientated and needs-led service. A high priority is given to client empowerment and local user forums.

The Dutch health care system operates at the district and national levels and is funded by a national social insurance scheme and provided free of charge by a range of statutory and non-statutory organisations. Services include a range of prevention, early detection and diagnosis, treatment and rehabilitation programmes. People with disabilities an their organisation are regularly involved in the planning and monitoring of services. A national rehabilitation programme exists and community based provision is provided at local levels. Support services are funded by the national and local government (municipalities) and a range of personal assistance and interpretation services are provided and financed through social insurance. People with disabilities and their families are involve in the planning and monitoring of services. Direct payments schemes exist for the provision of home based care and personal assistance for people with physical and sensory disabilities and people with intellectual disability.

The rights of disabled people are protected by a combination of special and general legislation. The law allows for legal remedy through courts and there are a number of non-judicial mechanisms that exist to promote non-discrimination. The general legislation applies to all categories of disabled persons with respect to education, employment, the right to marriage, the right to parenthood/family, political rights, access to court-of-law, right to privacy and property rights. There are also a number of guarantees to services in law including the right to medical care and other health care, training, rehabilitation and counselling, financial security, participation in decisions affecting them. The Netherlands has adopted the UN Standard Rules and implemented them through the Act on Facilities for the Disabled (WVG), was adopted and came into force in 1994. Since the adoption of the Rules the Government has been active in the dissemination of the Standard Rules, it has supported NGOs and has sought to integration the basic principles of the Standard Rules through a programme for an intersectoral policy on the disabled, 1995-1998.

Sweden

Sweden has a long social democratic tradition of universal services for its citizens that continue to be at one of the highest levels across Europe. The Swedish social democratic model is based on full employment, women's participation, active labour market policies and universal benefits based on notions of citizenship and entitlement, and social corporatism typified by social partnership approaches to policy making and bargaining. A high priority is now attached to the reform of welfare to reduce its abuses and adverse effects and to improve the effectiveness and efficiency of services. This has led to decentralisation of services to the local level, the greater involvement of user and community participation, and a partnership approach to service planning.

Swedish health and social services are governed under the provisions found in the *Social Services Act* and the *Health Care Act*. Sweden was the first European country to develop independent living and personal assistance for people with disabilities as part of social welfare policy, which have stressed integration into society.

Sweden provides a range of health and social services to people with disabilities including programmes for prevention, early detection and diagnosis, treatment and rehabilitation. Medical care is provide at local and County levels and is funded through social insurance. A range of support services are provided at local municipal levels including personal assistance and interpretation services which are provided free of change. A national rehabilitation programme exists and locally based rehabilitation services are provided for all people with disabilities. There is a high rate of participation of people with disabilities in the planning and monitoring of medical, social care and rehabilitation services.

Sweden has also committed itself to the full implementation of the UN Standard Rules. The Swedish Body of Organisations of Disabled People have worked in partnership with local authorities in drawing up guidelines for the practical implementation of the UN Standard Rules. These have been implemented through the new national disability policy *From Patient to Citizen: National Action Plan on Disability* which was launched in 2000. This made commitments to make existing public buildings and public places accessible to disabled people by 2010. Disabled people will also have the right to legal redress if local authorities fail to provide services that they are entitled to. A national accessibility centre is to be created and the government is committed to mainstreaming disability into all areas of life.

From Patient to Citizen: National Action Plan on Disability is a rights and citizenship based approach that encompasses the UN Standard Rules. This approach is seen as essential to guarantee the full participation of disabled people in society. The legislation covers a number of objectives for government which are considered to be essential if disabled people are to be guaranteed equal participation in society, dignified treatment and opportunities to make decisions affecting their own lives.

The objectives are:
• A social community based on diversity
• A society that allows people with disabilities of all ages to participate equally in the full life of the community
• Equal living conditions for girls and boys, women and men with disabilities

These will be achieved through
• Identify and remove obstacles to full participation in society
• Prevent and fight discrimination

- Make it possible for children, young people and adults with disabilities to lead independent lives and make decisions that affect their own lives.

The Swedish *Disability Act* provides for support and services to people with disabilities and the *Assistance Compensation Act* covers people with physical or mental disabilities. The Disability Act is complementary legislation and may not entail any curtailment of assistance to which the individual is entitled under other law. Since this is civil rights legislation and decisions can therefore be appealed in the administrative courts. The establishment of Disability Ombudsman has also worked within a rights based approaches and monitor disability legislation.

Under the Swedish *Social Services Act* of 1982, municipal social services were given greater responsibility for meeting the needs of people with disabilities and mental health difficulties, including acceptable housing and meaningful employment. A parliamentary commission in 1992 - the Committee on Psychiatric Care - concluded that social services were not being provided in a satisfactory manner. This led to further legislation, introduced in January 1995, which sought to provide for the social integration and quality of life for people with mental difficulties, on equal terms with the rest of the population.

The introduction of the *Support and Service for Persons with Certain Functional Impairments Act* on 1 January 1994 marked a new development in provisions concerning the support of adults with severe disabilities. It introduced the legal right to specified services and support for people with disabilities for families caring for disabled children. This includes rights to advice and personal support, personal assistant who can provide daily support, personal escorts, a contact person, relief service in the home, short stays away from home, short term minding for school children, foster homes and special housing for children and young people, special housing for adults and the right to daily activities. The principle is that relatives can be paid for their caring roles or have the right to a personal assistant to support them in such roles. The legislation is far-reaching and important because it provides recourse to action before the County Administrative Court. Of interest is that the Act was passed at a time when Sweden was cutting public services and in this light the legislation was seen to be critical to provide equality and basic rights for people with disabilities.

The Municipal Financial Responsibility Act requires municipalities to pay for the care of patients who have received medical treatment within the mental health in-patient system, but are still being cared for in hospital because they cannot be mainstreamed into the community into homes of their own with assisted living services. One of the aims of this responsibility is to stimulate the development of new forms of housing within the community for mentally disabled people who have been under long-term institutional care.

These laws have resulted in social investments in housing, daily occupation, work, recreation, rehabilitation, social interaction, health care and social welfare schemes. There are also specific state subsidies for the development of new services, for example, the development of support and interaction related to severely mentally ill substance abusers; family programmes with particular emphasis on family education, information and support; and the development of buddy support schemes with emphasis on user-led activities aimed at avoiding isolation and stimulating active recreation and better social networks

UK

The UK 'Beveridge' model has changed significantly since it was created in the late 1940s. The social democratic model based on universal principles has been substantially eroded and a liberal Anglo-Saxon model based on selectivity and residualism has been in evidence since the mid 1980s, based on principles of individualism, privatisation and marketisation of welfare provision. A change of government in 1997 introduced ideas of a 'third way' and new policies related to social inclusion, however, this has not resulted in any major restructuring of the neo-liberal structure that is firmly rooted in the UK. A number of reforms have been introduced to restructure local government services and employment services.

In the UK medical care is provide free of charge, funded by direct taxation and people with disabilities are treated as part of the general medical system. There exist a variety of programme for prevention, early detection and diagnosis, treatment and rehabilitation. Local authorities provide a range of social care and support services, including personal assistance and interpretation services that are funded by local authorities and means tested payments. In recent years there has been a significant emphasis on the participation of people with disabilities in the planning and monitoring of health and social care programmes. A major programme of monitoring and evaluation of the impact of services on people with disabilities has resulted in a range of performance indicators assessing the impact on equality and quality of life. The disability movement in the UK has been successful ensuring that here has been a growth of Centres for Independent Living, direct payments for personal assistance and services provided directly by people with disabilities. There is no national rehabilitation programme for people with disabilities; community based rehabilitation exists at local levels through primary health care, community based rehabilitation and through NGOs.

The *1990 National Health Service and Community Care Act* introduced care management and assessment processes. However, the legislation has seen a number of legal proceedings relating to budget management and the extent to which local authority resources should be allocated for services that are provided for in the legislation. A number of high profile cases led to the establishment by local authorities of eligibility criteria, which led to a rationing of resources earmarked for users who were most at risk. Other key legislation is the Disability Living Allowance and *Disability Working Allowance Act* 1991 and the *Disability Grants Act* 1993 which established the Independent Living Fund which allowed disabled people to be paid directly for services that they could then purchase, for example, for personal assistants. This legislation is likely to be extended in 2003 with a commitment by the government to make direct payments mandatory. A similar provision is currently being considered by the Scottish Executive. The 1998 *Human Rights Act* sets out rights and freedoms for the implementation of the European Convention on Human Rights also has the possibility of extending the provision of health and social care services and rights for people living in residential institutions. In practice, there are now more firmly rooted rights to community care under existing legislation and possibilities for litigation, including claims by disabled services users to locally based community services.

The 1995 Disability Discrimination Act was introduced as part of a recognition of the social model of disability and civil rights with provision to legal recourse in the event of discrimination. It covers employment, trade organisations, goods facilities, services and premises, education and transport. The Act was recently extended to cover education and accessibility of services. The Act will impact on health and social services through the provisions related to equality of access to services, for example,

the right to information in an accessible format and access to buildings and services.

In the UK a statutory duty exists under Disability Discrimination Act to ensure that there is accessibility in services provided to the public. In Northern Ireland, the statutory duty exists as a result of Section 75 of the Northern Ireland Act. This places a statutory requirement on public authorities to promote equality of opportunity, including disability. The Northern Ireland *Statutory Equality Duty* is a model of legally enforceable duties to promote equality in health by requiring public authorities to be proactive in mainstreaming equality, auditing their functions regarding equality and implementing new policies and practices to promote equality. The implementation of the statutory equality duty in Northern Ireland is considered to be one viable model that can be applied to health services whereby equality of opportunity can be promoted through equality schemes and Equality Impact Assessment. Schedule 9 paragraph 9 requires the public authorities to publish the results of equality impact assessments, ensuring that data and research information, the differential impact on groups, mitigating measures, consultation processes and monitoring systems are a matter of public information and are mainstreamed.

4. Improving the quality of health and social services for
disabled people

Improving the quality of services for disabled people

There is now a much greater emphasis given to improving the quality of health and social care for disabled people. This includes good practice in the development of quality through innovation and experimentation, coordination and integration initiatives, partnership approaches, the participation of users and the development of service quality initiatives (Pillinger, 2001). Much good practice has been developed internationally on a social model of disability much of which has been inspired by the UN Standard Rules and human rights based approaches to disability.

Evidence from the ESN Survey

The ESN survey found that many health and social service organisations have specific policies to meet the needs of disabled people, as well as mainstreaming disability through all service functions. For example:

- Essex County Council has a policy for people with physical and sensory disabilities called *Equal Lives.* This covers areas where the Council measures performance and both the implementation plan and targets are set annual in the Service Action Plan. This is carried out in conjunction with service users and partner agencies. Monitoring of the *Equal Lives* strategy takes place in consultation with service users.
- In the Royal Borough of Kingston, a range of policies have been introduced to provide better quality and inclusive disability services, including an Equal Opportunities Policy, staff training in anti-discrimination practices, a Disability Equality Policy (supported by a Disability Equality Group) and Disabled Parents Policy.
- In Sweden, Malmo City Council, has a city wide plan for disabled people which has the full involvement of disabled people. The framework for this follows from the national plan on disability.
- In the North Eastern Health Board in Ireland there is a policy on *Managing Equality and Diversity in the Work Place.* This has been important to the development of equality for disabled services users. An equal opportunity policy presently being developed. A personal outcomes measurement approach has been adopted as policy by the Board.

- Good practice in quality development includes the establishment of standards in health care for people with disabilities. For example, in Ireland a set of national standards have been developed for disability health services (National Disability Authority, 2001). User empowerment strategies have been growing in importance and have led to awareness-raising and information campaigns to highlight the problems faced by people with disabilities. The voice of disabled people has been growing in the last decade, as evidenced by networks of increasingly articulate disabled users' organisations nationally and across Europe. The development of quality systems for disability services has also stressed the importance of a user-focussed and user-driven perspective of quality and a more strategic approach.

Good practice examples

The following examples of good practice provide some interesting learning for the development of disability health and social services, particularly within a social model and in non-discriminatory ways.

Integrated approaches to health and social services: example from Lanarkshire Council

In Scotland, *Valuing People* is a new agenda for service provision for learning disabled children and adults using an integrated approach to health, social service and community provision in Lanarkshire (Lanarkshire Council, 2000) in order to plan high quality services including generic health and primary care services, which are integrated into specialist intellectual disability services. Features of success are a clear strategy/action plan; involving and listening to parents, carers and people with intellectual disability; listening to the needs of GPs, community nurses and practice staff; networking and learning from good practice; and working with enthusiastic staff.

Independent living and user-led initiatives

Pioneered by the American Independent Living Movement since the 1970s and the disability rights movement in Europe since the 1980s, independent living promotes the involvement of people with disabilities and their organisations in the development and running of services for people with disabilities. One of the major outcomes of this movement has been the development of Centres for Independent Living (CILs), which provide services directly to people with disabilities and their families. CILs have grown in importance in the UK, Sweden and Ireland. According to Adolf Ratzka, a disabled director of the Swedish Institute for Independent Living:

> Independent living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. Independent living does not mean that we want to do everything by ourselves…[it] demands the same choices and control in our everyday lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work in jobs that are in line with our education and abilities, start families of our own. Just as everybody else, we need to be in charge of our lives, think and speak for ourselves.

In 2002 the UK Disability Rights Commission (DRC) published a policy paper that is arguing for an enforceable right to independent living for all disabled people. The paper argues that "all organisations commissioning and providing services should be aware of the social model of disability and be fully committed to delivering services that enable choice, control, autonomy and participation" (Disability Rights Commission, 2002)

Assertive Outreach

Assertive outreach can reduce hospital admissions in frequency and duration, find and keep suitable accommodation, sustain family networks and improve social networks, improve general health, improve living and work skills, prevent relapse and ensure that help is provided at an early stage (Sainsbury Centre for Mental Health, 2003). Assertive outreach targets clients with severe mental health problems and who have difficulties engaging in services, through multidisciplinary team approach, intensive frequency of client contact, work with people in their own environments and with their own support networks. Assertive outreach is a new plank of the UK's NHS Mental Health policy that works within a social model by tackling social exclusion

through early intervention. It is anticipated that 50 assertive outreach teams will be established in the UK.

Participation of service users in the planning, development and monitoring of services

There is a greater emphasis now given to consultation with disability organisations, including participation in the planning, development and monitoring of services. There has been a growth of local, national and international disability user movements and networks of users and their associations. Despite a growth of initiatives on user participation and empowerment there remains limited evidence of systematic research to identify user needs. The bulk of the evaluation of services, including the quality of services, takes place from a provider perspective and methods of identifying user needs and preferences are not widespread. However, the increasing focus on users' rights has had an impact on user participation and the creation of standards that include rights and participation, including more individualised and tailored packages of care and greater user choice. There are different levels of user empowerment, participation and involvement exist and these can be identified on a continuum of: information, consultation, partnership, delegation and control. Examples of different approaches to user involvement and empowerment can be found in the box below.

Health and social service organisations have been under significant pressure to involve service users more effectively. Evidence from the ESN survey shows that:

• In the Royal Borough of Kingston disabled services users participate in a range of partnership boards, which exist between the local authority and the local Primary Care Trust in the health sector. They meet on a quarterly basis in order to plan and monitor services. The Disability Equality Group, which oversees implementation of the Disability Equality Policy and of the Disability Discrimination Act comprises disabled people, elected Members, Council officers. The Borough-wide Equal Opportunities Forum includes a representative of the local association of disabled people, Kingston Centre for Independent Living. A Disability Information Group exists to devise and disseminate information regarding disability issues, whose membership includes disabled people. Disabled people are consulted regularly. For example, an Information User Panel, which comprises disabled people who carry out quality checks on information to be issued to the public for its ease of understanding and usefulness. Users are involved in staff recruitment within Community Care Services and there are a range of users' forums including a Resource Centre for physically disabled people whose members' committee plays an active role in shaping the services and activities provided at the Centre.

• In Essex County Council a more proactive approach has been taken to involving young disabled people and young minority ethnic people in service planning and participation in Council activities. The Council has a Youth Service Equal Opportunities Policy and an Equality and Diversity Task group has been established to explore ways of improving services. This includes a Youth Service development day and events to celebrate cultural diversity and difference. A disability forum *Activate8* has been set up in partnership with the Social Services Learning Disability Team and Independent Living Team, service users and local groups. The aim is to improve consultation with people with young people with learning disabilities. A Disability Action Plan has also been developed for the youth service in order to improve access to services.

- In the Corporation of London there is a commitment to improve disability access under the Unitary Development Plan: "To require accessibility throughout the City for everyone unless it can be demonstrated that there are justifiable reasons for not doing so." Service users are involved in the planning and monitoring of services through the City of London Action Group which meets once a month and advises on practical aspects of access to services within the City. This year the Group is working with the Department of Community Services on the development of Direct Payments.

- In Ireland, all health boards consult with service users and there has been extensive consultations with disabled people and disability organisations in the drawing up of the recent national health strategy *Quality and Fairness,* in the development of a framework for new disability rights legislation under the auspices of the Disability Legislation Consultation Group and in the establishment of Disability Health Services Standards that have been drawn up by the National Disability Authority. Disability organisation express some disquiet about the extent of consultation that has taken place in recent years, with no real visible impact on change. At the health board level there are a variety of ways in which disabled service users participate in the development of services and there is a growth of interest in consumer panels and other feedback mechanisms. For example, in the North Eastern Health Board disabled service users participate in service planning and monitoring. This includes participation in services reviews, questionnaires, focus groups, and service audits. There are also Regional Consultative and Development Planning Committees and Regional Consultative Groups chaired by representative Voluntary Sector.

- In Sweden there are well-established systems for consulting with disabled services users in the planning of services. Focus groups and consumer panels are organised regularly to gain information about needs and ideas for the future development of services. In Ireland user consultation takes place through Regional Consultative Committees, user group meetings and consumer panels.

A Typology of User involvement

User involvement
- direct user influence (to varying degrees in most EU member states, but particularly the case in Denmark, UK, the Netherlands).
- *user panels/forums* on municipal and regional bodies (in Germany, the Netherlands, Sweden, Denmark and the UK)
- user involvement in service provision through family associations, care associations and advisory councils (in the UK, France, Greece, Portugal, Spain, Italy), and legal powers to conclude service agreements (Germany)
- user involvement in assessment of needs (increasingly the case in all countries, particularly in Germany, the Netherlands and the UK)
- user surveys and other feedback mechanisms to evaluate services (in the Netherlands, Sweden, Denmark, Italy, France and the UK)
- involvement of users as volunteers (all EU member states)
- user involvement through local partnership strategies, in evidence through local concertation pacts in Italy

User empowerment and choice
- budgetary autonomy to employ a carer (Austria, Germany, the Netherlands, Sweden, Luxembourg and the UK, and in some circumstances in Finland and Denmark); and user choice in service options (Germany, Luxembourg, Austria, the UK and the Netherlands, and increasingly the case in Sweden and Denmark)

In the UK, *Shaping Our Lives,* is a national user-controlled development project and network. It has been established by the National User Group and funded by the Department of Health and Joseph Rowntree Foundation to develop new thinking on service provision from a user perspective. The project is designed to place service users at the heart of the government's Quality Strategy for Social Care. It covers people with physical and sensory disability as well as mental health service users and survivors. Two other user-led projects have been established. First, *Our Voice in our Future* supports social care service users so that they can have a voice in welfare reforms. Second, is a project to support user involvement in the General Social Care Council and other social care bodies involved in regulating standards in social care.

Evidenced based service planning
An increasing emphasis is now placed on evidenced based service planning on the basis that needs assessments can help to provide a baseline profile of health needs and an evidence base for future service planning. This is practice that has been promoted by the European Observatory on Health Care Systems. Collating information on the effectiveness and costs of interventions, as well as considering equity and other factors can help ensure that resource allocation improves overall health outcomes. Evidence based practice needs to look not only at disability and mental health care services, but also at the influence of environmental factors such as housing, poverty, employment and social justice on disability and mental health.

Data and information systems
In the UK and Ireland services providers report on the existence of significant data gaps regarding services for people with disabilities and in the mapping of service provision. There are some worthy initiatives that have attempted to identify service needs and map services. For example, in Ireland the National Intellectual Disability Database and the National Physical and Sensory Disability Database have been established to assist with service planning and identify needs. However, there are concerns about the how far the databases capture all needs and in the case of physical and sensory disability the comprehensiveness of the database and its coverage. Nevertheless, they do offer a useful model for service planning.

Another key issue is that of mapping health and social services for disabled people. This is crucial for identifying gaps in services and equitable distribution of services geographically. In Ireland a recent research project for the National Disability Authority has established a methodology for disability health service mapping and this has been piloted in several health boards. In the UK a Mental Health Service mapping exercise is carried out on an annual basis in England. The objective is to monitor change and ensure greater equity of service provision in line with the government's national service framework on mental health. It consists of a national dataset covering key data and a web resource, which can be used by service providers in localities as a tool for local needs assessment, service and workforce planning.

5. The Employment of Disabled People and Managing Disability Diversity

This section looks at how health and social service organisations have improved the management of disability and particularly the support, mentoring and career development of disabled staff. Unlike the previous ESN report on Race prepared for the Manchester Workshop, there appear to be fewer examples of initiatives to support and develop disabled staff, particularly into managerial and senior positions. Nevertheless, the diversity in the workforce in the public sector has become an increasingly important objective that is linked to two important goals notably the improvement of equity within organisations and improvements in services delivery.

Many governments, health and social service agencies are now implementing or considering plans for diversity in organisations by implementing greater workforce diversity for people with disabilities, and in some cases at managerial and senior levels. The objective is to match the public sector workforce to the customer base and the profile of the community at all levels. In some countries specific performance objectives have been developed and diversity management plans have been developed. This section begins with a discussion of employment policies for people with disabilities and then goes on to look at the management of disability diversity.

Integrating disabled people into work

Integrating people with disabilities and mental health difficulties into mainstream employment has resulted in a shift of policy away from sheltered workshops to more active, coordinated and supported training and employment projects in most European countries. For example:

- Developing supported work programmes for occupationally disadvantaged people in Sweden has been tied in to the need to support independence and autonomy and thereby reduce dependency.

- In Austria, policies to integrate disabled people into the labour market have led to new supported employment schemes and work integration measures which are facilitated by the reorganisation of Federal Social Offices that allow for more coordination between services.

- In 1999, new legislation in Italy established the right of disabled people to work. The right to supervised work placement was strengthened for adults with mental health and learning disabilities by making provinces responsible for planning and shaping employment policies. The responsibilities of employment services, local authority social and welfare services and work placement services are structured and regulated, which should help to pave the way for the provision of personalised routes for the placement of disabled persons in work.

Employment policies for disabled people

There are a significant number of employment policies for disabled people many of which have been influenced by the EU's Employment Guidelines as well as national developments. These include:

- Special schemes to provide work experience
- Start-up grants to set up own business and self-employment.

- The adaptation of the work place, through grants for work adaptation and of technical aids
- Personalised support with grants for a tutor, job coach or a personal assistant in the enterprise

The low level of disabled people in the workforce is a consequence of a range of factors. A recent study European study found that only 30.5 % of the disabled labour force population is employed. The rest is either unemployed (20.8%) or inactive (42%) (Grammenos, 2003). A further study by the European Disability Federation (2002) reported on the main reasons for the high rates of unemployment and inactivity of disabled people. These are related to:

- Prejudice of employers
- Lack of education and training
- Severity of their disability, followed by the lack of adaptation of the workplace
- Lack of psychological support and guidance
- Existence of a "benefit trap" preventing disabled people accessing jobs, without losing income support
- Low pay (57% of disabled people reported that they are in low paid work)
- Barriers, including physical/architectonical barriers, and communication barriers.
- In addition, significant barriers are experienced by disabled people in accessing health, social services and employment services. This is principally due to a communications barriers and attitudinal and social barriers.

In practice very few health and social services organisations have disabled people in senior and managerial positions. The percentage of the workforce that is disabled is also relatively small. The ESN survey found that this ranged between 1% and 3% of the total workforce.

Disability issues have been raised in the EU National Action Plans on Employment. Since 1998, the Employment Guidelines and the associated National Action Plans for employment have stressed the important of removing barriers to enable disabled people to enter and be retained employment. Particular importance has been given to removing barrier to full participation in working life and to developing policies that combat discrimination and promote the integration of disabled people into work.

A number of countries have introduced job creation programmes and special supports, incentives or subsidies for the employment of disabled. In addition, there are also duties and requirements on public bodies in a large number of countries to employ disabled people through quotas.

Most EU member states and Norway have legislation concerning discrimination on the grounds of disability and/or specific laws, which regulate various aspects of the employment of people with disabilities. Discrimination at work on the grounds of disability is prohibited by the constitutions of Finland, Greece, Italy, Portugal and Spain. Specific laws forbid such discrimination either as part of general anti-discrimination legislation (Denmark and Ireland), or through specific legislation (France, Spain, Sweden and the UK). Several countries have specific laws which contain various measures related to the occupational integration of disabled people, most notably addressing the issues of employment quotas, protection against dismissal and, to a lesser extent, regulation of pay.

A compulsory quota, enforceable by legislation, for the recruitment of disabled people in the private and private sectors exists in Austria, Belgium, France, Germany, Greece, Italy, Luxembourg, the Netherlands and Spain. In Austria, France, Germany,

Luxembourg and Spain a levy is imposed on employers which do not meet the quota and in Austria, Germany and Luxembourg employers may also be fined if they violate their duty to employ disabled people. Tax exemptions and other financial incentives for employers that recruit disabled people exist. Ireland and Portugal have a quota system for the employment of disabled people, but these are not regulated by law. Special rules on protection against dismissal for people with disabilities exist in Austria, France, Germany, Spain, Sweden and the UK. In addition, some countries have introduced provisions on the adaptation of the workplace, training and other subsidies, as well as in-kind support for people with disabilities. In Austria, the "Comeback Service" funded by the Labour Market Service (AMS) arranges and provides incentives for employers and subsidises wage costs. In Italy, in order to limit the marginalisation of disadvantaged persons, national and regional legislation have set norms for the granting of economic benefits or tax allowances to enterprises employing disadvantaged people. Further examples include:

Appendix 5 provides a summary of the main provisions concerning the employment of disabled people.

Managing disability in the workplace

A greater emphasis is now being given to managing disability at work as a means to improve the quality of the workforce and its ability to deliver to customers in effective ways. The ILO Code of Practice on Managing Disability in the Workplace is an example of the importance now attached to managing disability.

ILO Code of Practice Managing Disability in the Workplace, 2002

The ILO has developed a Code of Practice to guide employers in adopting positive strategies in managing disability in the workplace with a view to

a) ensuring that people with disabilities have equal opportunities in the workplace;
b) improving employment prospects for persons with disabilities by facilitating recruitment, return to work, job retention and opportunities for advancement;
c) promoting a safe, accessible and health workplace;
d) assuring that employer costs associated with disability among employees are minimised – including health care and insurance payments, in some instances;
e) maximising the contribution that workers with disabilities can make to the enterprise.

The code of practice covers issues concerning the development of disability strategies in the workplace, covering recruitment, interviewing, orientation to the job, work experience, work trials, promotion, career development, training, review and appraisal, job retention, accessibility, adaptation of workplaces, and incentives and support services

The Code of Practices says that "Employers should consider the management of disability issues in the workplace a priority task which contributes to the business success, and regard it as an integral part of the workplace human resources development strategy". It goes on to say that this should "maximise the contributions and abilities of all staff, including those with disability.

There is now a greater attention given to the recruitment and employment of people with disabilities in non-discriminatory ways. For example, local authorities in the UK categorise all job applicants by gender, race and disability at the application, shortlist

and appointment stages of recruitment. They also categorise the workforce by gender, grade, ethnicity and age.

In similar ways there has been the development of equality proofing and reviewing of workplaces in the UK, Ireland and Sweden. One study on equality proofing the performance review system in the civil service in the UK identified different performance markings for disabled and non-disabled staff. This has helped to identify the need for more career profiling of disabled staff and the need to identify areas of dissatisfaction and disadvantaged faced by disabled staff. This would be very relevant to health and social services (Tamkin P, Rick J, Bates P (2000) *Equality Proofing in Performance Review in the Civil Service,* IES: Brighton). Similarly in Sweden the national leadership development strategy has highlighted the important of ensuring that women, disabled people and non-Swedish national have access to leadership training, including mentorship and training.

A recent research study *Equality and Diversity in Local Government* by the local government employers association the LGMB, examined the ways in which local authorities has developed diversity policies in order to assess what practices work in the three main areas. The research found significant variations in the extent to which equality and diversity practices have been put in place, with greatest attention given to gender and disability issues. Disability access was seen as less contentious than issues concerning Race. The findings are as follows:

- Representation, participation and leadership: many elected members of councils do not represent the diversity of the population that they serve. This is seen to be partly an issue of national political parties to address as well as ensuring that the selection of locally elected councillors takes account of equality and diversity issues.

- Structures, committee organisation and staff: the survey found many good practices regarding the recruitment of staff, training and development of staff. However, the lack of a coordinated and strategic approach to equality and diversity in the organisation was seen as a major factor impeding the development of equality and diversity outcomes. Senior level commitment and clear lines of responsibility were seen to be crucial to equality and diversity outcomes. This included the need for visible commitment at the head of the organisation and an effective system of performance management.

- Service procurement, delivery and impact: this areas is seen as more difficult to implement than staffing issues. Some Councils were found to lack the expertise in providing equality and diversity services and had problems monitoring the impact of services on specific groups. Nevertheless the procurement process was seen as a mechanism to promote equality and diversity. Inspection regimes often stress processes rather than outcomes and this tended to miss the impact on the end user of services.

Recommendations concerned the need to develop a more strategic approach and build best practice, foster leadership and cultural change, improve community engagement and support progress (LGMB, 2003).

A further development is the that of integrating equality and diversity into quality improvement programmes, that also impact on the. In the UK the Equality Standard in Local Government recognises the importance of fair and equal treatment in local government services and employment and has been developed as a tool to enable authorities to mainstream gender, race and disability into council policy and practice

at all levels. The aim is to remove the institutional processes and barriers that prevent equality and the full and equal participation of disabled people, minority ethnic people and women. The Standard provides a systematic framework for the mainstreaming of equalities which is designed to assist local authorities in meeting legal obligations and encourage the development of anti-discrimination practice appropriate to local circumstances and a framework for improving performance over time. It is based on the principles of quality, leadership and community involvement.

Appendix 6 provides an outline of the main features of the standard and a checklist for organisations to consider in meeting the Equality Standard in Local Government.

Equality opportunities policies, processes and practices

Equal opportunities monitoring has become an important to the overall achievement of equality in the workplace. This means going beyond the collection and analysis of data to assessing the effectiveness of an organisation's policies, processes and practices. It can help to provide a picture of the composition of the workforce, where particular groups are under-represented and help organisations to make the best use of their staff.

Equal opportunities monitoring covers:

• recruitment procedures
• staff in post and by grade
• job application rates
• job allocation
• personal review and appraisal
• eligibility and application for promotion
• success rates in promotion
• career development
• take up of training and development programmes
• resignation rates and reasons

Cabinet Office (1999) *Equal Opportunities Monitoring Guidance*

Guidance has also been provided by the World Health Organisation (2001) on the development of disabled people in the workplace:

• Human resource planning to ensure the optimum mix of health professionals in order to provide the best quality service.
• Disability awareness training for health personnel.
• Training programmes should stress the importance of the principle of the full participation and equality for people with disabilities.
• Training programmes to be developed in consultation with people with disabilities and people with disabilities should be involved as teachers, instructors and advisors in staff training programmes.

The management of disability in the workplace is also seen to have business as well as social benefits. For people who have mental health difficulties there are a range of institutional and attitudinal barriers to working in mainstream employment and in retaining jobs during and after treatment. In some countries the development of good mental health practices has become part of human resources management policy and occupational health policies. This is partly a recognition of the role that work can play in promoting good mental health. For example, in Germany "corporate health

promotion" has been an important part of public service employment and health and wellness at work. This has been fed into work organisation and work design and has resulted in a "health circle" approach whereby all key stakeholders are brought together to identify ways of improving wellness in the workplace.

In the UK local authorities are engaged in workforce development with an emphasis on providing skills development and training for their front line employees, leadership development, employee development and addressing skills shortages. An increasing number of local authorities are striving to become "Learning Local Authorities" and striving to gain status as "Investors in People". In the health services the *Improving Working Lives* initiative that has developed out of *Agenda For Change: the NHS Plan*, and the development of the innovative University for the NHS are driving forward a lifelong learning agenda.

The NHS has also been trying to establish better employment practices for disabled people. *Looking Beyond Labels - Widening the employment opportunities for disabled people in the new NHS* (April 2000) is a practical guide to NHS employers on the recruitment and retention of disabled staff in the NHS. The guide aims to assist NHS employers to recruit more people with a disability; develop flexible working practices to accommodate disabled workers; and promote greater understanding of disabled employees in the workplace.

The UK employment service have also created the *disability symbol* for employers who are demonstrating good practice in disability employment. Employers who use the symbol make five commitments:

- To interview all disabled job applicants who meet the minimum criteria for a job vacancy, and consider them on their abilities.
- To ask disabled employees, at least once a year, what can be done to make sure they can develop and use their abilities at work.
- To make every effort to keep staff in their jobs should they become disabled.
- To ensure that key employees develop the awareness needed to make the commitments work.
- To review these commitments annually, to plan improvement and to tell all employees about achievement and future plans.

Evidence from the ESN Survey

The ESN survey found that workplace policies to support the employment and career development of disabled people exist in a large number of health and social service organisations.

- In the Royal Kingston Borough there are a variety of policies to promote the employment and career development of disabled people through the Equal Opportunities Policy, Anti-discriminatory Practice training, Recruitment and Selection processes and procedures developed for disabled people, and Disability Awareness Training for staff. There are also Occupational Health workplace assessments for new employees with disabilities. RKB also produces Disability Equality policy Action Plans and Equality Scheme Action Plans and Access audits undertaken in preparation for the full implementation of the DDA.

- In Ireland, the policies of the North Eastern Health Board that have been developed to support the employment and career development of people with disabilities have been formulated on the basis of the Employment Equality

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Legislation 1998 and 2000. There is a Code of Practice on Recruitment, a Recruitment Policy and an Equal Opportunities and Diversity Policy. An organisation wide survey of attitudes, and current practices in relation to equality and diversity was completed in late 2002. The findings from this are being collated for inclusion in the 2004 Action Plan.

- In the Corporation of London, Guildhall, there are a range of policies to support the employment and career development of people with disabilities, including the inclusion of disabilities in the Council's "Equal Opportunities in Employment Policy" laying the basis for non-discriminatory behaviour in all employment functions. The Council provides Disability awareness training for managers to enable them to identify issues and areas where they can assist the employment and career development of people with disabilities. The Council has been attempting to mainstream particular actions to support the employment and career development of disabled people into all employment policies and procedures. These actions are summarised for managers in a document entitled "Management Guidelines to Policies & Procedures concerning People with Disabilities" and include special provisions around recruitment, re-deployment and the appraisal process.

- The Council has met a number of obligations in earn the "Two Tick Symbol" by undertaking to offer an interview to ALL candidates with disabilities who meet the minimum selection criteria for a post; to prioritise the re-deployment of all employees with disabilities who are subject to potential redundancy or in need of re-deployment due to health/capability reasons (subject only to legal requirements concerning the priori case of women returning from maternity leave); and to ensure that all managers discuss the development needs of employees with disabilities during the regular appraisal process.

Example: UK Health Care programmes on managing and promoting diversity within the organisation

The Equalities Framework for the UK National Health Service (NHS), *The Vital Connection*, was launched in April 2000. It covers a package of indicators, standards and monitoring arrangements and sets national targets for the NHS from April 2000 on disability, tackling harassment, achieving a representative workforce and board training on equality and diversity. These have since been incorporated into the Human Resources Performance Framework for the NHS and the Improving Working Lives Standard.

The main goals of the Equalities Framework are:

- A workforce for equality and diversity: To recruit, develop and retain a workforce that is able to deliver high quality services that are accessible, responsive and appropriate to meet the diverse needs of different groups and individuals.
- A better place to work: To ensure that the NHS is a fair employer achieving equality of opportunity and outcomes in the workplace.
- A service using its leverage to make a difference
- To ensure that the NHS uses its influence and resources as an employer to make a difference to the life opportunities and the health of its local community, especially those who are shut out or disadvantaged.

The main building blocks for change are leadership for equality and diversity, monitoring and evaluation, involving stakeholders, and a partnership approach. This

is also encouraging organisations to establish equalities statements, standards and indicators.

In addition, the UK NHS Programme on Diversity *Positively Diverse* has been established to promote diversity in health service employment with the following objectives:

• Widen access in local communities to the NHS workforce
• Improve the working lives of staff through tackling harassment, discrimination and inequality
• Make staff feel valued and confident to voice concerns
• Develop a workforce better able to deliver accessible services appropriate to local needs

The programme has also established a *Positively Diverse* process covering six stages. The stages provide a strategic framework for tackling diversity in health care employment and covers six stages from planning and preparation through to measuring progress. A number of pilot sites are using this process which involves sending out a questionnaire to their staff and carrying out a strategic analysis to determine what the organisation should look like and devise solutions for how to get there. Findings are disseminated to staff as well as senior managers of the organisations. The whole process takes up to a year to complete.

Example: Two Ticks Accreditation, North Mersey Community NHS Trust

A range of solutions adopted by North Mersey Community NHS Trust focused on improving the working environment for disabled people. The Trust received accreditation and became a Two Ticks symbol user in 1995 to show that the organisation is Positive about employing and supporting disabled people. Work towards accreditation helps an organisation to take a fresh look at its approach to employing disabled people. It shows job applicants with disabilities that they are welcomed for their abilities. It shows existing employees that they are valued. The organisation implements a series of measures that means that disabled people really are welcomed and valued. Commitments, implemented across the whole organisation, help to structure action and let disabled people know what they can expect. North Mersey Community NHS Trust accepted the symbol's commitments:

• To interview all applicants with a disability who meet the minimum criteria for a job vacancy and consider them on their abilities;
• To ensure there is a mechanism in place to discuss with disabled employees what you and they can do to make sure they can develop and use their abilities;
• To make every effort when employees become disabled to keep them in employment;
• To take action to ensure that all employees develop the appropriate level of disability awareness needed to make your commitments work;
• Each year, to review the commitments, what has been achieved, plan ways to improve on them and let employees know about progress and future plans**.**

Source: NHS (2000) *Positively Diverse*

A further activity that concerns disability is a programme to widen employment opportunities for disabled people in the NHS. *Looking Beyond Labels: Widening Employment Opportunities for Disabled People in the new NHS* is a guide produced by the UK Government to help organisations recruit and retain disabled staff. It

covers staff retention, recruitment and selection, monitoring effectiveness, staff training and development, problem areas and solution, and practical help and advice. The guide outlines the business case for equality and diversity for disabled people on the basis that this enables organisations to use people's talents to the full and ensure that selection decisions and policies are based on objective criteria, and not on unlawful discrimination, prejudice or unfair assumptions. This also helps an organisation to get closer to customers and understanding their needs as well s make the organisation more attractive to customers and clients.

The follow two examples of guidance have been reproduced from the guide:

Recruitment and selection checklist
*   Are job requirements strictly related to the needs of the job?
*   Do your job advertisements state that you positively welcome applications from disabled candidates?
*   Do you place all jobs with the your local Job Centre and ensure that the Disability Employment Adviser (DEA) is aware of all vacancies?
*   Do you inform local disability organisations of job vacancies?
*   Is all your job application forms and recruitment literature accessible to disabled people?
*   Do you have the capability to deal with applications in alternative
*   formats?
*   Do you operate a guarantee interview scheme for all disabled candidates who meet the minimum criteria? Do you state this on advertisements?
*   Do you ask interview candidates in advance whether they have any special needs?
*   Is reception staff fully briefed in advance?
*   Have interviewers received disability awareness training?

Making a commitment – checklist
*   Does your organisation have an Equal Opportunities Policy, or
*   Diversity statement, and does that policy specifically refer to disability?
*   Is your policy communicated to all staff? Have they been involved in its formulation?
*   Is your policy well advertised? And to whom?
*   Is progress in equal opportunities reviewed regularly by your Board and senior management?
*   Are you a user of the Positive about Disabled symbol?

6. Conclusion

Promoting the competence of health and social services to be delivered in a framework of diversity is closely related to the structure of the health care system and whether rights to services have been established. For example, in Sweden the high quality, accessible health and social care system exists in the wider context of a universal welfare state that promotes the dual objectives of free and universal health care with equality of access for all. This has led to a wide range of social supports, including some of the most progressive systems of independent living and personal assistance. However, this model has not been so effective in relation to access into employment for people with disabilities.

User involvement and participation in the planning and monitoring of services is closely linked to the development of empowerment and independence as guiding principles in service delivery. Whilst accessible and high quality health and social care services are an essential component of good practice, it is important that they operate within a social model of disability and place the user at the centre of the service. A key role for the future of health and social care services is to ensure that there is integration and coordination with the full range of services that are essential for participation in society. An important issue is the development of more effective evaluation and information systems so that service needs can be identified and translated into service planning and workforce planning.

Providing for more diverse workplaces and more accessible and user focussed services means exploring how barriers to participation can be overcome, how user-led, advocacy and participatory approaches can promote choice and autonomy, how unmet needs can be identified and met, and how quality criteria can lead to real improvements in both the employment of people with disabilities and in improving access to services.

An important issue is the development of more effective evaluation and information systems so that service needs can be identified and translated into service planning and workforce planning. This is essential to the provision of quality services that map services as they develop and measures issues such as equity of service provision, local needs assessment, service and workforce planning.

In the area of managing diversity within the organisation there are a number of key issues to address, particularly because of the low level of employment of disabled people in health and social service organisations, particularly at senior levels. This means making sure that organisations are more accommodating of equality and diversity, including the development, assessment and implementation of policies relating to staff with disabilities within a broad diversity framework. There is also a need for better knowledge and awareness about the benefits of valuing and accommodating diversity in the area of disability so that disability issues can be mainstreamed throughout all areas of the organisation and championed at senior levels. Similarly there is a need to establish fora for employees with disabilities for the exchange of ideas, good practices and for support and mechanisms to support and develop staff. Finally, raising the awareness of everyone in the organisation will be important to promoting a culture that accommodates and promotes diversity.

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APPENDIX 1: DECLARATION OF THE SOCIAL PARTNERS ON THE EMPLOYMENT OF PEOPLE WITH DISABILITIES

Preamble

UNICE/UEAPME, CEEP and the ETUC fully recognise the challenge of improving employment opportunities for people with disabilities on the open labour market. As representatives of employers and workers at European level these organisations would like to make a contribution to promoting the occupational integration of people with disabilities in Europe.

In 1997, the social partners undertook to collect examples of good practices adopted by companies to improve integration and retaining of people with disabilities. They gave preference to examples of partnership initiatives, though they did not exclude unilateral initiatives taken by employers or trade unions. The result of this exercise was a collection of case studies from the open labour market, involving companies of all sizes throughout the European Union in various sectors of activity.

The ETUC, CEEP and UNICE/UEAPME addressed their compendium on the employment of people with disabilities to the European summit in Vienna in December 1998. The social partners believe including the promotion of employment of people with disabilities in the employment guidelines is the right approach. This declaration supplements the collection of case studies and attempts to draw some lessons from the experience gained on this occasion. By identifying solutions to the challenges posed to both employees and employers, the social partners intend to make a useful contribution to the debate, thus expressing their commitment to the occupational integration of people with disabilities.

Promoting equal opportunities for people with disabilities

The ETUC, CEEP and UNICE/UEAPME believe that an equal approach is the right path to follow in order to improve the employment opportunities of people with disabilities in the open labour market. Discrimination based on factors which are irrelevant to the task in question is socially unacceptable and economically inappropriate. It is detrimental to the individual concerned, to good work relations and to the efficiency of the company.

Emphasising ability, not disability

The determinant factor for a person's success on the labour market is their ability, whether he/she is disabled or not. A Selection based on abilities avoids problems related to preferential treatment for one or other group of employees.

In the first place, the emphasis on an individual's skills makes it possible to improve the opportunities of developing their potential and facilitates their acceptance and integration into the working environment. Furthermore, only a recruitment policy based on skills can improve a company's competitiveness and its capacity to create jobs.

Promoting the employment of people with disabilities: a positive factor for the company

Good employment practices can contribute to the economic success of a company. Through actively promoting the employment of people with disabilities, companies can develop previously unexploited resources and increase their potential for innovation.

Increased awareness and a greater understanding of disability in companies may lead to the development and marketing of products and services which are better suited to the needs of consumers, including consumers with disabilities. The latter represent a diversified market of more than 30 million people Europe-wide. The participation of employees with disabilities in the development of these products and services can favour the emergence of new markets.

Improving work relations by taking account of disability questions

Companies with a high level of awareness of disability are better equipped to respond to the needs of disabled employees. Taking these needs into account allows the employees concerned to carry out their tasks and duties more successfully. Employing people with disabilities can thus bring added value to the company and the staff as a whole.

Diversified approaches require made-to-measure solutions

The definition of disability varies considerably from one European country to another and reflects the diversity of social and cultural approaches to the issue. For this reason, the legal framework and integration policies for people with disabilities at the workplace also vary from one Member State to another. This diversity is important to ensure that policies are suited to the needs of each individual and to the cultural, social and economic environment.

From the point of view of employment, a number of factors must be taken into consideration.

- Firstly, disability comes in many forms. This alone means that there must be a variety of specific, personalised measures, which is incompatible with a policy of "categorisation".
- Secondly, companies which employ people with disabilities range in size from micro-enterprises to large businesses. The size of the business may have a significant impact on the kind of obstacles encountered and the solutions given to encourage the inclusion of people with disabilities in the workplace.
- Thirdly, the nature of the sector and the occupation also influence what measures can and should be taken, in matching the ability of the individual with the specifics of the task.

The wealth of practices in this field reflects the diversity of situations. In order to facilitate awareness of the challenges and opportunities linked to the employment of people with disabilities, it is important to disseminate information and encourage exchange at European level.

Encouraging employment by acting outside the workplace.

Many aspects of the physical and cultural environment outside the workplace affect the chances of people with disabilities gaining employment. Policies aimed at removing societal barriers for people with disabilities are needed

For example,

- The school environment is not always adequate for children with disabilities, creating problems for them in later life. Without access to equal levels of education, the aspirations and employability of the disabled adult are fundamentally impaired.
- Means of transport which are unsuitable for a considerable proportion of people with disabilities are a major obstacle to their inclusion in the labour market and in society.
- The architectural design of the physical environment, particularly residential accommodation, public buildings and workplaces, has a major impact on the occupational integration of people with disabilities.
- Attitudes and prejudices with regard to disability, notably in public opinion and the media, influence disabled persons' perception of their own abilities and the way they are perceived by employers, work colleagues, the professions, service providers and customers.
- The measures that need to be taken involve various players whose respective responsibilities vary depending on their field of action. However, dialogue between these various stakeholders, public authorities, non-governmental organisations and social partners is essential to put in place appropriate and effective policies and to bring an end to prejudice and discrimination.

Recommendations for the employment of people with disabilities

To improve employment opportunities for disabled people in Europe, CEEP, UNICE/UEAPME and the ETUC recommend that:

- employers envisage developing equal opportunity policies for people with disabilities and make these policies known to all management and employees, with particular emphasis on raising the awareness of recruitment and human resources.
- trade unions endeavour to examine disability issues with their members and develop equal opportunity policies in this area.

The social partners, at the appropriate level, will seek to promote among their members equal opportunity policies in favour of persons with disabilities taking account of the following elements:

- make known when recruitment notices are published that candidates with disabilities will be considered solely on the basis of their abilities
- ensure that selection and recruitment procedures are not discriminatory and allow disabled people to apply and take part in the recruitment process;
- ensure that career possibilities are open to disabled employees on the same basis as to other staff members, according to their abilities and potential, and that employees with disabilities have equal access to training;
- offer support to employees who become disabled so that they can keep their position or find one which corresponds to their experience and abilities .
- ensure that the implementation of the policies adopted is followed up and evaluated .

UNICE/UEAPME, CEEP and the ETUC invite the public authorities to:

- take account of the needs of disabled people in an integrated way in order to create a culture of inclusion rather than separation;

- encourage the various players whose responsibilities have an impact on the employability of people with disabilities to work together and make concerted efforts to improving effectively the physical, educational and cultural environment of people with disabilities;
- publicise the wide range of innovations in this area and encourage their exchange across Europe.

APPENDIX 2: THE MADRID DECLARATION "NON DISCRIMINATION PLUS POSITIVE ACTION RESULTS IN SOCIAL INCLUSION"

We, over 600 participants in the European Congress on Disability, meeting in Madrid, warmly welcome the proclamation of 2003 as the European Year of People with Disabilities as an event, which must act to raise public awareness of the rights of more than 50 million Europeans with disabilities.

We set down in this Declaration our vision, which should provide a conceptual framework for action for the European Year at European community level, national, regional and local level.

PREAMBLE

DISABILITY IS A HUMAN RIGHTS ISSUE
Disabled people are entitled to the same human rights as all other citizens. The first article of the Universal Declaration on Human Rights states: All human beings are free and equal in dignity and rights. In order to achieve this goal, all communities should celebrate the diversity within their communities and seek to ensure that disabled people can enjoy the full range of human rights: civil, political, social, economical and cultural as acknowledged by the different international Conventions, the EU Treaty and in the different national constitutions.

DISABLED PEOPLE WANT EQUAL OPPORTUNITIES AND NOT CHARITY
As with many other regions in the world, the European Union has moved a long way during these last decades from the philosophy of paternalism towards disabled people to one of attempting to empower them to exercise control over their own lives. The old approaches based largely on pity and perceived helplessness of disabled people are now considered unacceptable. Action is shifting from an emphasis on rehabilitating the individual so they may 'fit in' to society towards a global philosophy of modifying society to include and accommodate the needs of all persons, including people with disabilities. Disabled people are demanding equal opportunities and access to all societal resources, i.e. inclusive education, new technologies, health and social services, sports and leisure activities, consumer goods and services.

BARRIERS IN SOCIETY LEAD TO DISCRIMINATION AND SOCIAL EXCLUSION
The way our societies are organised often means disabled people are not able to fully enjoy their human rights and that they are socially excluded. The statistical data that is available shows that disabled people have unacceptable low levels of education and employment. This also results in greater numbers of disabled people living in situations of real poverty compared with non-disabled citizens.

DISABLED PEOPLE: THE INVISIBLE CITIZENS
The discrimination disabled people face is sometimes based on prejudice against them, but more often it is caused by the fact that disabled people are largely forgotten and ignored and this results in the creation and reinforcement of environmental and attitudinal barriers which prevent disabled people from taking part in society.

DISABLED PEOPLE FORM A DIVERSE GROUP
As with all spheres of society, disabled people form a very diverse group of people and only policies that respect this diversity will work. In particular, people with

complex dependency needs and their families require particular action by societies, as they are often the most forgotten among disabled people. Also, women with disabilities and disabled people from ethnic minorities are often faced with double and even multiple discrimination, resulting from the interaction of the discrimination caused by their disability and the discrimination resulting from their gender or ethnic origin. For deaf people the recognition of sign language is a fundamental issue.

NON DISCRIMINATION + POSITIVE ACTION = SOCIAL INCLUSION
The recently adopted EU Charter of Fundamental Rights acknowledges that to achieve equality for disabled people the right not to be discriminated against has to be complemented by the right to benefit from measures designed to ensure their independence, integration and participation in the life of the community. This synthesis approach has been the guiding principle of the Madrid congress that brought together more than 600 participants in March 2002.

OUR VISION
Our vision can best be described as a contrast between this new vision and the old vision it seeks to replace:

• Away from disabled people as objects of charity… and Towards disabled people as rights holders.
• Away from people with disabilities as patients… and Towards people with disabilities as independent citizens and consumers.
• Away from professionals taking decisions on behalf of disabled people …and Towards independent decision making and taking responsibilities by disabled people and their organisations on issues which concern them.
• Away from a focus on merely individual impairments…and Towards removing barriers, revising social norms, policies, cultures and promoting a supportive and accessible environment.
• Away from labelling people as dependants or unemployable… and Towards an emphasis on ability and the provision of active support measures.
• Away from designing economic and social processes for the few… and Towards designing a flexible world for the many.
• Away from unnecessary segregation in education, employment and other spheres of life …and Towards integration of disabled people into the mainstream.
• Away from disability policy as an issue that affects special ministries only….and Towards inclusion of disability policy as an overall government responsibility.

INCLUSIVE SOCIETY FOR ALL
Implementing our vision will benefit not only disabled people but also society as a whole. A society that shuts out a number of its members is an impoverished society. Actions to improve conditions for disabled people will lead to the design of a flexible world for all. "*What is done in the name of disability today will have meaning for all in the world's tomorrow*".

We, the participants in the European Congress on Disability, meeting in Madrid, share this vision and request all stakeholders to consider the European Year of People with Disabilities in 2003 as the start of a process that will make this vision a reality. 50 million European disabled people expect us to give an impulse to the process to make this happen.

OUR PROGRAM TO ACHIEVE THIS VISION

LEGAL MEASURES

Comprehensive anti-discrimination legislation must be enacted without delay to remove existing barriers and avoid the establishment of new barriers that disabled people may encounter such as in education, employment and access to goods and services and which prevent disabled people from achieving their full potential for social participation and independence. The non-discrimination clause, Article 13 of the EC Treaty allows this to happen at Community level, thus contributing to a real barrier-free Europe for people with disabilities.

CHANGING ATTITUDES
Anti-discrimination legislation has proven to be successful in bringing about changes in attitude towards people with disabilities. However, the law is not enough. Without a strong commitment from all society, including the active participation of disabled people and their organisations in securing their own rights, legislation remains an empty shell. Public education is therefore necessary to back up legislative measures and to increase understanding of the needs and rights of disabled people in society and to fight the prejudice and stigmatisation that still presently exists.

SERVICES THAT PROMOTE INDEPENDENT LIVING
Achieving the goal of equal access and participation also requires that resources should be channelled in such a way as to enhance the disabled person's capacity for participation and their right to independent living. Many disabled people require support services in their daily lives. These services must be quality services based on the needs of disabled people and must be integrated in society and not be a source of segregation. Such support is in accordance with the European social model of solidarity – a model that acknowledges our collective responsibility towards one another and especially towards those who require assistance.

SUPPORT TO FAMILIES
The family of disabled people, in particular of disabled children and people with complex dependency needs unable to represent themselves, plays a vital role in their education and social inclusion. In view of this, adequate measures for families need to be established by public authorities, in order to allow families to organise their support for the disabled person in the most inclusive way.

SPECIAL ATTENTION TO DISABLED WOMEN
The European Year has to be seen as the opportunity to consider the situation of disabled women from a new perspective. The social exclusion faced by disabled women cannot only by explained by her disability but also the gender element needs to be considered. The multiple discrimination faced by disabled women has to be challenged through a combination of mainstreaming measures and positive action measures designed in consultation with disabled women.

MAINSTREAMING OF DISABILITY
Disabled people should have access to the mainstream health, education, vocational and social services and all the opportunities, which are available to non-disabled persons. The implementation of an inclusive approach to disability and disabled people requires changes in current practice at several levels. First of all, it is necessary to ensure that services available to disabled people are co-ordinated within and across the different sectors. The accessibility needs of the different groups of disabled people need to be considered in the planning process of any activity and not as an afterthought when the planning has already been completed. The needs of disabled people and their families are varied and it is important to devise a comprehensive response, which takes into account both the whole person and the various aspects of his or her life.

EMPLOYMENT AS A KEY FOR SOCIAL INCLUSION
Special efforts need to be made to promote the access of disabled people to employment, preferably in the mainstream labour market. This is one of the important ways to fight against the social exclusion of disabled people and to promote their independent living and dignity. This requires, not only the active mobilisation of the social partners, but also of the public authorities, which need to continue to strengthen the measures already in place.

NOTHING ABOUT DISABLED PEOPLE WITHOUT DISABLED PEOPLE
The Year must be an opportunity to grant disabled people, their families, their advocates and their associations a new and expanded political and social scope, at all levels of society, in order to engage governments in dialogue, decision-making and progress around the goals for equality and inclusion.
All actions should be undertaken in dialogue and co-operation with the relevant representative disability organisations. Such participation should not only be limited to receiving information or endorsing decisions. Rather, at all levels of decision-making, governments must put in place or strengthen regular mechanisms for consultation and dialogue enabling disabled people through their disability organisations to contribute to the planning, implementation, monitoring and evaluation of all the actions.
A strong alliance between Governments and disability organisations is the basic requisite to progress most effectively the equal opportunities and social participation of disabled people.
In order to facilitate this process, the capacity of disability organisations should be enhanced through greater resource allocation to allow them to improve their management and campaigning capacities. This also implies the responsibility on part of the disability organisations to continuously improve their levels of governance and representativeness.

SUGGESTIONS FOR ACTION

The European Year of People with Disabilities 2003 should mean an advancement of the disability agenda and this requires the active support of all relevant stakeholders in a wide partnership approach. Therefore concrete suggestions for action are proposed for all relevant stakeholders. These actions are to be established in the European Year and continued beyond the European Year; progress should be evaluated over time.

EU AUTHORITIES AND NATIONAL AUTHORITIES IN EU AND ACCESSION COUNTRIES
Public authorities should lead by example and therefore are the first but not only actor in this process. They should:-
- review the current scope of Community and national legal frameworks aiming at combating discriminatory practices in the fields of education, employment and access to good and services;
- initiate investigations into those restrictions and discriminatory barriers that limit the freedom of disabled people to fully participate in society, and to take whatever measures are necessary to remedy the situation.
 - review the services and benefits system to ensure that these policies assist and encourage disabled people to remain and/or become an integral part of the society wherein they live.
- undertake investigations on violence and abuse committed against disabled people, with particular attention to those disabled people living in large institutions.
- strengthen legislation on accessibility to ensure that disabled people have the same right of access to all public and social facilities as other people.

- contribute to the promotion of the human rights of disabled people at world wide level by participating actively in the work to prepare a UN Convention on the rights of disabled people.
- contribute to the situation of disabled people in developing countries by including the social inclusion of disabled people as an objective of the national and EU development co-operation policies

LOCAL AUTHORITIES
The European Year must really occur firstly at the local level, where issues are real to citizens and where associations of and for people with disabilities are doing most of their work. Every effort must be made to focus the promotion, resources, and activities at the local level.
Local actors should be invited to integrate the needs of people with disabilities in urban and community policy, including education, employment, housing, transport, health and social services, bearing in mind the diversity of disabled people, including, among others, older people, women and immigrants.
Local governments should draft local plans of action on disability in co-operation with representatives of disabled people and set up their own local committees to spearhead the activities of the Year.

DISABILITY ORGANISATIONS
Disability organisations, as representatives of disabled people, have a major responsibility to ensure the success of the European Year. They have to consider themselves as the ambassadors of the European Year and proactively approach all relevant stakeholders proposing concrete measures and seeking to establish long lasting partnerships when these not yet exist.

EMPLOYERS
Employers should increase their efforts to include, retain and promote disabled people in their workforce and to design their products and services in a way that these are accessible to disabled people. Employers should review their internal policies to ensure that none of these prevents disabled people from enjoying equal opportunities. Employer organisations can contribute to these efforts by collecting the many examples of good practice that already exist.

TRADE UNIONS
Trade unions should increase their involvement to improve the access to and maintenance in employment of disabled people and ensure that disabled people benefit from equal access to the training and promotion measures, when negotiating the agreements in the companies and professional sectors. Also increased attention should be paid to promote the participation and representation of disabled workers, both within their own decision making structures and those existing in the companies or professional sectors.

MEDIA
The Media should create and strengthen partnerships with associations of people with disabilities, in order to improve the portrayal of disabled people in mass media. More information on disabled people should be included in the media in recognition of the existence of human diversity. When referring to disability issues, the media should avoid any patronising or humiliating approaches but focus instead on the barriers disabled people face and the positive contribution to society disabled people can make once these barriers have been overcome.

EDUCATION SYSTEM

Schools should take a leading role in spreading the message of understanding and acceptance of disabled people's rights, helping to dispel fears, myths and misconceptions and supporting the efforts of the whole community. Educational resources to help pupils to develop a sense of individuality with regard to disability in themselves and others, and to help them recognise differences more positively should be developed and widely disseminated.

It is necessary to achieve education for all based on the principles of full participation and equality. Education plays a key role in defining the future for everybody, both from a personal point of view, as well as a social and professional one. The education system has, therefore, to be the key place to ensure personal development and social inclusion, which will allow children and youngsters with disabilities to be as independent as possible. The education system is the first step towards an inclusive society.

Schools, colleges, universities should, in co-operation with disability activists, initiate lectures and workshops aimed at raising awareness of disability issues among journalists, advertisers, architects, employers, social and health care-givers, family care-givers, volunteers, and members of local government.

A COMMON EFFORT TO WHICH ALL CAN AND SHOULD CONTRIBUTE

Disabled people seek to be present in all spheres of life and that requires that all organisations review their practices to ensure that they are designed in a way that disabled people can contribute to them and benefit from them. Examples of such organisations include: consumer organisations, youth organisations, religious organisations, cultural organisations, other social organisations that represent specific groups of citizens. It is also important to involve places such as museums, theatres, cinemas, parks, stadiums, congress centres, shopping malls and post offices.

We, the participants at the Madrid congress support this Declaration and commit ourselves to disseminate it widely, so it may reach the grass roots, and we will encourage all relevant stakeholders to endorse this Declaration before, during or after the European Year of People with Disabilities. By endorsing this Declaration, we organisations state openly our agreement with the vision of the Madrid Declaration and commit to undertake actions that will contribute to the process that will bring about real equality for all disabled people and their families.

If your organisation wishes to endorse this Declaration and wishes to publicise this endorsement, it should inform the European Disability Forum (info@edf-feph.org), which will then include your organisation on a special section of its website
(www. edf-feph.org) devoted to the endorsement of the Madrid Declaration.

Appendix 3: International instruments impacting on disability rights: Council of Europe, United Nations, World Health Organisation

Council of Europe

The most important instruments impacting on disability are:

- *European Convention on Human Rights and Fundamental Freedoms (ECHR).* The Convention has been important in developing case law in a key number of areas impacting on disability, under liberty, fair trail, inhuman or degrading treatment and mental disability. A non-discrimination clause fails to explicitly cover disability.

- The *European Social Charter of 1961(amended in 1996).* Most of the principles in the European Social Charter have relevance to disability. They include the opportunity to earn a living in an occupation freely entered into (principle 1), the right to just conditions of work (principle 2), the right to appropriate facilities for vocational training (principle 10), the right to benefit from measures enabling the person to enjoy the highest possible standard of health attainable (principle 11), the right to benefit from social services (principle 14). Principle 15 states that disabled people have the right to vocational training, rehabilitation and resettlement. States are required to take a range of measures concerning employment "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".

- *Council of Europe Convention of the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Biomedicine and Human Rights (1997).* Although the Convention has a number of shortcomings it states that there should be protection for the dignity and identity of all human beings and [to] guarantee everyone, *without discrimination*, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.

- *Council of Europe Convention on the Prevention of Torture and Inhuman and Degrading Treatment (1987) and Disability (CPT).* This Convention has been important in the context of people with disabilities who are incarcerated in a mental institution or other residential care.

- *Partial Agreement in the Social and Public Health Field.* This has led to the discussion of a range of disability matters (including discrimination based on disability) by the Committee on the Rehabilitation and Integration of People with Disabilities (CDPRR).

- *Recommendation of the Committee of Ministers on the adaptation of health care services to the demand for health care and health care services of people in marginal situations (2001).* This includes people with disabilities along with other groups who live in marginal situations and advocates the development of integrated and coherent social and health policies and measures to reducing inequalities in health. This is based on principles of human rights and patient's

rights, human dignity, social cohesion, democracy, solidarity, equality, participation and freedom of choice.

- *Recommendation on a Coherent Policy for Persons with Disabilities.* This recommendation aims to implement the principle of equal opportunities and non-discrimination principles found in the UN Standard Rules regarding prevention, active participation in community life and independence. This includes a number of aims, for example, involvement in the planning and implementation of rehabilitation and integration proceses, full citizenship and access to all institutions and services in the community, independence and self-determination and particular attention to the situation faced by women and older people with disabilities. It covers general policy, prevention and health education, identification and diagnosis, treatment and therapeutic aids, education, vocational issues, employment, social integration, protection, training of personnel, information, statistics and research.

- *Recommendation Concerning the Legal Protection of Persons Suffering from Mental Disorder Placed as Involuntary Patients and Subsequent Developments.* This recommendation results from the 1997 White Paper on the protection of the human rights and dignity of people with mental disorder, especially those placed as involuntary patients in an institution. At the time it was recommended that Member States review their legislation and administrative rules on the confinement of the mentally ill by reducing to the minimum the practice of compulsory detention. The Recommendation was agreed in the light of a number of important cases in the European Court of Human Rights. The Recommendation covers the grounds for involuntary loss of liberty and the rights of those subjected to this power. A further Recommendation in 1994 on psychiatry and human rights updated the principles within a human rights context.

- *Recommendation on a Charter on the Vocational Assessment of People with Disabilities.* This recommendation argues for 'the greatest possible measure of social and economic participation as well as independence'.

International measures: the UN and the WHO

United Nations

The international policy agenda is important in both reinforcing and establishing good practice regarding national disability policies. Disability is now part of the mainstream international human rights agenda the emergence of which was marked by the 1975 UN General Assembly Declaration on the Rights of Disabled Persons. This was followed by International Year of Disabled Persons in 1981 and the development of a World Programme of Action. In 1985 the Universal Declaration of Human rights was extended to include disabled people and in 1993 the UN *Rules on the Equalization of Opportunities for Disabled Persons* addressed participation in eight specific areas: accessibility, education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion. Similarly the importance of the social model of disability was reinforced by the UN in 1994 in that "…society creates a handicap when it fails to accommodate the diversity of all its members" and "People with disability often encounter attitudinal and environmental barriers that prevent their full, equal and active participation in society" (United Nations, 1994, paragraphs 3 and 4). By 1995, the implementation of the Standard Rules had led to the reformulation of thinking on disability issues at the national level in a large number of countries, where they have been used as a benchmark to guide good practice in a social model of disability

The Standard Rules place responsibilities on government bodies in evaluating and implementing national programmes. Many countries have taken the Standard Rules as their explicit frame of reference. The Finnish Government was the first country to adopt the Standard Rules in its legislation in 1993 and in 1998 the Greek government incorporated the Standard Rules into national law. In Norway, UN Standard Rule 3 on Rehabilitation is based on the rights of individuals to define their own goals and that services shall assist and stimulate the responsibilities and efforts of the individuals to gain well-being. This is in a framework of community based provision, local community involvement and coordination of services. An Action Plan for disabled people is based on a social model of disability which recognises the limitations on the local environment and which places responsibilities on local authorities and other bodies to ensure the full participation of disabled people (WHO, 2001).

Other relevant instruments include the Proposed new UN *Convention on the Rights of People with Disabilities* which is being discussed in by the UN Ad Hoc Committee set up by UN Resolution 56/168 to "consider proposals for a comprehensive and integral international convention to protect and promote the rights and dignity of persons with disabilities". The proposed *UN Convention on the Rights of People with Disabilities* aims to give legal protection to rights for people with disabilities by building on the UN Standard Rules which have been the principal international instrument designed to protect the rights of people with disabilities. However, the Standard Rules are voluntary and there is little scope for recourse where violations or non-application occurs. In other areas the UN has adopted legally binding conventions to protect against human rights violations for disadvantaged groups, for example, covering women and refugees. An international Convention on the Rights of People with Disabilities is proposed to form the central component of this international legal framework, providing in amongst other areas the right to a decent education, the right to vote, the right to due process, the right to participate in the life of the community. There appears to be growing international backing for the introduction of the Convention, including backing from the European Union.

World Health Organisation
The World Health Organisation, established as the health arm of the UN in 1948, has the objective, of the attainment by all peoples of the highest possible level of health. Health is defined in WHO's Constitution as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. According to the WHO the limited participation of disabled people in school, work and social activities is no longer viewed as a result of their impairments, but as a result of societal barriers to their participation. The rights of people with disabilities to have the same opportunities as others in their communities and societies are now well recognized. Despite the increased awareness about the community participation of people with disabilities and the developing policies and legislation related to disability, there are still many disabled people who do not have adequate opportunities to access rehabilitation services to attend school, to achieve income producing work, or to participate in activities characteristic of their communities.

The WHO has also established a classification for the functioning, health and disability of people. The ICF (International Classification of Functioning, Disability and Health) was established in order to focus attention on quality of life, health and social policies to improve access and treatment, and take account of social aspects of disability by focussing on the impact of the social and physical environment on a persons functioning. Initiatives in the WHO impacting on the development of good practice at the national level include

the 2001 campaign on mental health, and annual report 2001 focused on "*Mental Health: New Understanding, New Hope"*, includes recommendations about what states should do to improve mental health care.

APPENDIX 4: OVERVIEW OF HEALTH AND SOCIAL SERVICE PROVISION IN THE MEMBER STATES OF THE EU

Austria

Based on a social insurance model with an emphasis on monetary transfers to compensate for disability, illness, unemployment or old age. Responsibilities for the health and social services are split between centrally funded and provided services, which are regionally or locally delivered (health and labour market) and local care services (via the federal states). The nine federal states have responsibility for providing social assistance, care of the elderly, infirm and disabled, nursery schools and other care services. There is also a welfare mix with direct service provision by non-profit associations and a greater emphasis on active labour market policies. Significant recent reforms in health and social services include the introduction of a uniform national care allowance and greater user involvement in services.

Belgium

A comprehensive social insurance scheme, which is organised via mutual insurance companies (through two main types of mutuality: socialist and catholic). They provide both income assistance and services. A wide range of organisations including charities, local authorities, companies and religious communities provide health and social services. A new generation of services are developing on principles of deinstitutionalisation, demedicalisation, collective and community work and the involvement of users. The state plays an important role in the regulation and supervision of services. Significant responsibilities are also given to local authorities, who remain the primary providers of local services, through Public Welfare Centres who are able to coordinate local services.

Denmark

A universalistic social democratic model that is primarily public sector led and provided, and funded through taxation. It is based on principles of universalism, equality and redistribution. This model has been open to criticism and scrutiny in recent years for its financial burden, inefficiency and paternalism. There are increasing problems of waiting lists, concerns about a growing number of unsupported vulnerable groups, concerns about the legitimacy of the model, and a breaking of the consensus over the welfare model that has dominated the post-war Danish welfare system. In contrast to other Scandinavian countries the Danish model places a higher priority on social services than on social security benefits. The majority of services are provided at the local level (social services) or the regional level (health).

France

The French model is based on two principles: insurance and assistance. Health and social services are provided through a complex structure of state provision with a large number of services decentralised to local authorities, departmental authorities, and social and socio-medical institutions. The public sector remains a major provider of income related and social services. The operation of assistance and insurance has led to problems with a dual system where responsibilities are divided between the government, regional and local authorities. An increasing number of services are now delegated by the government to the private sector and non-profit associations. The French Government is responsible for the approval and regulation of these organisations.

Finland

Based on a Nordic model of welfare with roots in Protestantism and democracy and a political tradition of social democracy. This has emphasised the role of the state in providing universal services and a basic minimum income for all. The main features of the Finnish model are comprehensive policies, social rights derived from citizenship, the public sector as the main provider, earnings-related and flat-rate income benefits, public provision of services financed by taxation, equality, and the redistribution of income. However, high unemployment in Finland over the last decade and the associated need to introduce cost-effective expenditure strategies has led to some limits on the system, for instance, through the introduction of income-related charges and eligibility conditions for some services. Like Sweden and Denmark, large numbers of women work in the health and social services and they are assisted by family policies and child and elder care provisions. Health and social services are decentralised to Finnish municipalities.

Germany

A strong emphasis is given to entitlements to monetary transfers under German law, exemplified by the introduction of care insurance. The provision of health and social services and the rights and entitlements to services by users, particularly those who are disadvantaged, is less well defined. Health and social services are provided by a mix of provision by first, the public authorities (social insurance, local municipal, rural and commune services, and regional and sub-regional services provided by the *Lander* (federal states)); second non-profit providers (made up of six independent federations of welfare providers, churches and other religious communities, and other welfare providers); and third private commercial providers. An internationally unique structure of welfare cooperation exists whereby independent welfare associations in the non-profit sector and more recently the private sector have legal status. The independent sector provides the bulk of social services under the principle of *institutional subsidiarity* and there has been significant expansion of services in recent years as services have diversified and specialised within a relatively sound financial base. The traditional role given to the family in social service provision has been augmented by additional professional support as care needs have increased and as more women have participated in the paid labour market. Increased attention is now being given to user needs, quality assurance and coordination of services.

Greece

A rudimentary model with low levels of expenditure on health and social services (compared to the EU average). The current structure was established after the fall of the dictatorship in 1974 and subsequent attempts to modernise social and welfare systems. There exists a lack of a systematic service policy to inform the development of health and social services, with an emphasis on the treatment of social problems rather than prevention. The state sector is described as outdated and dysfunctional, with the dominance of an administrative rather than a service culture. The highly centralised state sector is increasingly being replaced by decentralisation and a mixed economy provision including private and non-profit organisations involved in service delivery and local government have recently become important agencies for delivering a wide range of services, although with limited autonomy from central government. The role of the state is currently being reshaped with partnerships between central and local government and between the public and private sector.

Ireland

Health and social services are provided through a combination of state, voluntary and charitable organisations and in recent years there has been growing pressure to coordinate these various services. Although Ireland's health and social services have led increasingly to an institutional model with a growth of statutory services, their origins lie in church, charitable and voluntary provision, which has increasingly been

regulated and funded by the state. In Ireland the voluntary and community sector have always been significant providers of community-based services. In this respect the development of the social economy is seen as a positive way forward. In contrast to other European countries, it has been slower to decentralise services and the bulk of its health and social services remain centralised and delivered within a national framework.

Italy

The Italian welfare model is rudimentary with a strong emphasis on familial support structures. Services are highly fragmented, under-developed and there are significant regional inequalities in the distribution of services, particularly between the north and south of the country. Major reforms were introduced in Italy in the 1990s in order to reduce budget deficits and improve public finance. Reductions in public expenditure and increases in public revenue led to a surplus in the late 1990s. Italy spends a high proportion of its public expenditure on social security, whereas expenditure on services like health, education and active labour policies account for a far smaller proportion of GDP. Decentralised powers and responsibilities allow for a great deal of local autonomy in service planning and in local tax raising powers. The regions have legislative powers over health and welfare, whereas the local authorities are responsible for delivering or funding health and social services. Recently employment services were transferred to the regions.

Luxembourg

Luxembourg has developed a comprehensive range of health and social services, many of which are provided directly by private and voluntary organisations with state funding. The problems in coordinating these diverse and unregulated arrangements led to legislative reform in 1998. The social security system in Luxembourg evolved over a relatively long period of time to include all groups in the population. Like other European countries the growth of social security expenditure has risen to 30 per cent of GDP. Forty per cent of funding of social security comes from the state, with employer and employee contributions forming the rest; social security now takes up about 50 per cent of entire benefits followed by health insurance.

The Netherlands

The Netherlands is characterised by a social democratic model with high levels of welfare spending and access to universal and comprehensive benefits, although influenced by Christian Democratic ideology and a social insurance model. The social partnership model between government and interest groups have introduced wage moderation, control of public spending and control on social security has had some remarkable successes. This led to an agreement to trade off wage moderation for an increase in jobs between the social partners, a reform of the social security system, including cost containment, cuts and measures to reintegrate people into work. The 'polder model' also led to new systems of consultation, discussion and consensus building activities that were also applied to the health service through systems of self-administration at local levels, alongside the introduction of marketisation of services. The Netherlands has highly decentralised services, a high level of provision and its services are universal. The bulk of welfare is provided by non-profit organisations who are funded by the state, local authorities and social insurance. These organisations have moved from being charities to professional service providers. The emphasis is on public funding and private provision of care and the development of a market-orientated and needs-led service. A high priority is given to client empowerment and local user forums.

Portugal

Portugal's particular relationship to its citizens and the provision of services is rooted in its recent history. Portugal emerged from an authoritarian regime in 1974 with a modern democratic system, with citizens rights firmly embedded in the constitution and a new system of social partnership. For this reason the development of health and social services has taken place relatively quickly. In recent years Portugal has moved into a vigorous era of public sector management reforms as it has begun to grapple with a new role of a modern state that is increasingly orientating its services to citizens needs. The Portuguese Economic and Social Council firmly embedded trade union, employer and government relations into this model. Successive governments have, until recently, promoted the role of the state as the main provider of services, in a decentralised system based on democratically elected local municipal executives, assemblies with local legislative powers, and neighborhood councils at sub-municipal levels. The success of the reforms introduced post-1974 are reflected in the universal provision of health care and education. However, Portugal remains a highly centralised country and in practice the municipalities have relatively limited powers. Portuguese is based on informal family and church provided services in the care field. More recently the expansion of health and social services has taken place by increasing the role of private sector initiatives and their management to the private social solidarity institutions (IPSS).

Spain

Democratisation in the 1970s inherited a weak social protection system with limited work-related coverage. The introduction of political and social rights coincided with a deteriorating social and economic context. As a result the constitutional guarantees, for example, the right to work and the right to social housing were not safeguarded in practice. The Spanish constitution asserts a number of important social values, including the values of freedom and justice, equality and political pluralism, with certain goals established for the health and social services. The resulting regime is a mix of universal typified by the recent introduction of universal health care, and work-related systems, alongside private enterprise roles, although it remains rudimentary in its coverage. There is now a greater emphasis on active employment policies. The development of welfare services established under the Constitution was matched by political and administrative decentralisation leading to a high degree of regional autonomy with responsibilities laid down by central government alongside powers to pass supplementary legislation with responsibilities for delivery of health and social services at a regional level. Although municipalities enjoy a degree of financial and administrative autonomy, they have few powers and scarce resources.

Sweden

Sweden has a long social democratic tradition of universal services for its citizens that continue to be at one of the highest levels across Europe. However, Sweden's public debt doubled in the early 1990s, unemployment tripled and the budget deficit increased ten-fold to 10 per cent of GDP, at that time the highest of all EU countries. The Swedish social democratic model is based on full employment, women's participation, active labour market policies and universal benefits based on notions of citizenship and entitlement, and social corporatism typified by social partnership approaches to policy making and bargaining. The beginning of a break up of the model can be seen from the downturn in Swedish economic performance, rising budget deficits and massive increases in employment, although the model remains intact, and that privatisation is only considered where this results in cost-effectiveness and improved efficiency. As a result a high priority is now attached to the reform of welfare to reduce its abuses and adverse effects and to improve the effectiveness and efficiency of services. This has led to decentralisation of services to the local level, the greater involvement of user and community participation, and a partnership approach to service planning.

UK

The UK 'Beveridge' model has changed significantly since it was created in the late 1940s. The social democratic model based on universal principles has been substantially eroded and a liberal Anglo-Saxon model based on selectivity and residualism has been in evidence since the mid 1980s, based on principles of individualism, privatisation and marketisation of welfare provision. A change of government in 1997 has introduced ideas of a 'third way' and new policies related to social inclusion, however, this has not resulted in any major restructuring of the neo-liberal structure that is firmly rooted in the UK. A number of reforms have been introduced to restructure local government services and employment services.

APPENDIX 5: SUMMARY OF THE MAIN LEGAL PROVISION CONCERNING THE EMPLOYMENT OF PEOPLE WITH DISABILITIES

Country	Constitutional provisions	Statutory provisions	Quota for employment of PWD	Specific employment supports for PWD	Statutory disability body
Austria	Article 7(1) states: "No person may be discriminated against on the grounds of his or her disability. The Republic (Federation, provincial authorities and local authorities) undertakes to guarantee the equal treatment of disabled and non-disabled persons in all areas of daily life". This has to be applied by the legislative authorities and this was carried out in 1999 under Federal Law which eliminated provisions discriminating against disabled people.	Under administrative penal law, a fine can be imposed on anyone unjustifiably discriminating against persons or restricting their access to public places or services on the grounds of, among others, their disability. One provision enables local authorities to withdraw operating licences from business owners who discriminate against any disabled person. Under the Disabled Persons' Employment Act registered disabled people have special protection against dismissal and protection of remuneration in the event of the onset of a disability. A representative for the disabled is required in enterprises employing at least five disabled workers. The long-term objective is to include disabled people in mainstream employment support services. There is a four percent quota obligation for employers with a staff of over 25. Financial support to employers is available under the Act.	√	√	No
Belgium	Covered under general provision of equality under the law	A collective agreement on the recruitment and selection of workers covers discrimination based on disability. Employment services for the employment of disabled people are provided for under the Social Rehabilitation Act of 1963 which set up the National Fund for the Social Rehabilitation of Disabled People, including funding for technical aids and access. There are a variety of subsidies and grants for private and/or public sector employers.	√	√	No
Denmark	Article 75 (2) of the Constitution of the Kingdom of Denmark Act 5th June, 1953 states that "Any person unable to support himself or his dependants	Danish disability policy seeks to give disabled people equal opportunities on the labour market through the provision of support, aids, personal assistance and wage subsidies to employers. The main objective of disability policy in the labour	No	√	No

	shall, where no other person is responsible for his or their maintenance, be entitled to receive public assistance provided that he complies with the obligations imposed by Statute in this respect".	market is to provide for equality and removing the barriers to equal participation. The public employment service can provide financial support for the recruitment of a personal assistant for employees and self-employed persons with a disability providing special assistance in connection with the performance of their job. Municipalities and the public employment service may also grant financial support to disabled persons in employment or in training with special tools and technical aids which may be necessary to perform the work or participate in training. In addition, public authorities have a duty to give disabled persons priority in all jobs they are able to perform. Disabled people who have completed their education can be recruited as trainees with public or private employers and support and personal assistance is provided. Disabled persons who are not able to find employment in the ordinary labour market, but whose working capacity is not sufficiently reduced to make them qualify for anticipatory social pension, may be employed in so-called "flex" jobs. Most collective agreements in both the public and the private sector now include special provisions, so-called social chapters, which make it possible to make special provisions for disabled employees.			
Germany	Article 3 (3) of the Basic law of the Federal Republic of Germany states that " No person shall be favoured or disfavoured on the basis of sex, parentage, race, language, homeland and origin, faith or religion or political opinion. No person shall be disfavoured because of disability".	At the federal level, the Ministry of Labour and Social Affairs is responsible for vocational integration and laws relating to disabled people. There are special centres for vocational rehabilitation, financed and run by a range of organisations including the federal Government. Specialists at local employment offices arrange placements with employers and if employers choose to register a vacancy with the employment office it must be checked for suitability for a disabled person. In some areas, special programmes exist for the placement of disabled people in permanent public sector jobs. New placement models include 'specialist integration services' to ease transition from sheltered workshops or unemployment. Legal obligations and rights are also set out in the Severely	No	√	No

		Disabled Persons Act. Employers are required to examine every vacant post for suitability for a severely disabled worker and they must employ severely disabled people in a way that enables them to use and develop their abilities to the full. Seriously disabled people also enjoy a special level of protection against dismissal under the act. Under the Works Constitution Act, the works council has the duty to promote the rehabilitation of disabled people in the establishment. The employer must supply comprehensive information to the works council in good time to enable it to discharge its duties.			
Greece	A constitutional principle of equality under Article 4.1 states that "all Greeks are equal before the law"	Policy in the field of vocational training and employment is linked with the principle of equal opportunities and 'a promise that disabled people can and must contribute to the country's social and economic development'. Compulsory employment was introduced in 1979 in the public sector and extended to the private sector in 1986. The quota obligation applies to any organisation operating in Greece which employs over 50 staff; such organisations must fill a total of seven per cent of jobs with disabled people and other disadvantaged groups. In 1995, an administrative penalty was introduced for cases where employers fail to respect the law. Extra obligations apply to the filling of public-sector vacancies. In banks, the public sector and local authorities, a proportion of vacancies in specified ancillary occupations must be reserved for people protected by law. One in four lawyers in public occupations must be a person protected by the law. In addition, in banks and the public sector, switchboard vacancies must be filled by a certain percentage of blind people.	√	√	No
France	No specific provisions	French labour law includes a number of provisions aiming to prevent discrimination under the ground of disability. Company rules and regulations may not be prejudicial to employees in their employment or work on grounds of their disability, and no person may be excluded from recruitment procedures, disciplined or dismissed on grounds of their disability, although an exception is made where a doctor certifies that the disabled person is not suitable for the work in question. Legislation passed in 1991	√	√	No

		included several measures to improve access to public establishments, workplaces and places of residence and education. The law ensures that account is taken of all types of disability. Controls were imposed on the construction of public buildings. Certain provisions in the Penal Code relate specifically to discrimination.			
Ireland	No specific provisions	Legislation passed in 1992 sought to remove obstacles, improve access and make it possible for disabled people to benefit from mainstream services and facilities. Legislation passed in 1999 sets out a list of norms governing the rights of disabled people at work. A compulsory employment scheme exists with quotas for separate categories of disadvantaged people. Employers who are do not implement the quota for economic reasons must contribute a sum into a regional fund promoting employment for disabled. Private and public employers who ignore their obligations under the 1999 law and fail to provide documentation demonstrating that they have fulfilled these, are subject to heavy fines.	√	√	√
Italy	Article 3: "It is the responsibility of the Republic to remove all obstacles of an economic and social nature which, by limiting the freedom and equality of citizens, prevent the full development of the individual and the participation of all workers in the political, economic and social organisation of the country." Article 4 recognises the right of all citizens to work and perform, in accordance with their abilities and preferences, work which contributes to the material or spiritual development of society. Article 38 states that "Any citizen unable to work and lacking the means necessary to live has a right to maintenance and social assistance."	Legislation passed in 1992 sought to remove obstacles, improve access and make it possible for disabled people to benefit from mainstream services and facilities. Legislation passed in 1999 sets out a list of norms governing the rights of disabled people at work. A compulsory employment scheme exists with quotas for separate categories of disadvantaged people. Employers who are do not implement the quota for economic reasons must contribute a sum into a regional fund promoting employment for disabled. Private and public employers who ignore their obligations under the 1999 law and fail to provide documentation demonstrating that they have fulfilled these, are subject to heavy fines.	√	√	

Luxembourg	No specific provisions	The 1991 law on disabled workers regulates disabled people's rights in employment. To qualify under the law, a person must be recognised as disabled by the authorities and registered. If a disabled person declines a post or training measures proposed by the authorities, they lose the right to employment under the quota scheme. Employers with a staff of at least 25 must employ at least one full-time disabled worker. Those with a staff of at least 50 must meet a two per cent quota and those with at least 300 staff must meet a four percent quota. The amended Penal Law also covers discrimination on grounds of disability.	√	√	No
The Netherlands	Article 1 of the Constitution all persons in the Netherlands are to be treated equally in equal circumstances. Disability is not explicitly mentioned, but discrimination on the grounds of religion, belief, political opinion, race or sex or any other grounds whatsoever is prohibited.	In the 1980s reforms were carried out to place new obligations on, and incentives to, the economic players to assist the return to work of disability benefit recipients and to prevent workers who become disabled from entering the benefit system. The Employment Service provides vocational guidance and training, brokerage and placement, and other assistance to unemployed job seekers. The municipalities have administrative responsibility for directly subsidised job creation schemes, including sheltered workshops and supported employment schemes. The 1998 Act on the reintegration of disabled persons into work aims to increase the participation of disabled persons in the labour market and prevents unemployment by more efficient administrative procedures in applications for subsidies and by minimising financial risks for employers, as well as measures for disabled persons, such as additional income (in the event of lower pay), training facilities and individual job coaching.	No		No
Portugal	According to Article 71 (2) of the Constitution of the Portuguese Republic "the State shall carry out a national policy for the prevention and for the treatment, rehabilitation and	The law of 1989 aims to promote constitutional rights in the fields of disability prevention, treatment, rehabilitation and equal opportunities. It lays down six fundamental principles in all aspects of life affecting disabled people which guide rehabilitation policy, including equal opportunities in areas such as employment. The	√	√	No

	integration of disabled persons, shall develop a form of education to make society aware of its duties of respect for them and solidarity with them and to ensure that they enjoy their rights fully, without prejudice to the rights and duties of their parents or guardians".	law also lays down the policy aims of state institutions in health, education, social security, vocational training, employment, transport, housing and public buildings, fiscal arrangements and culture, sport and recreation. The intention is to create a network of services linking health, education, social security and employment. Firms employing a staff of at least 20 are obliged to give priority in recruitment to persons permanently incapacitated as a result of accidents occurring in their service, providing them with work compatible with their disability. Employers receive financial assistance including compensation for a period of reduced performance while adapting to the job, reduction of employers' social security charges, lump-sum integration awards and grants for the adaptation of work stations and elimination of obstructions in buildings. Employers may apply for reimbursement of payments to personnel contracted to provide follow-up and support to disabled persons through the process of integration for up to six months.			
Finland	According to section 5, paragraph 2 of the Finnish Constitution, no person shall, without reasonable grounds, be afforded a different status on account of, among other grounds, disability.	Finland has no quota or preferential employment policies and no anti-discrimination legislation for disabled persons. People who have lost partial working capacity while in employment are very well protected and employers are required to make a 'tailor-made' job for such persons. However, after one year of partial incapacity related to sickness, the employer has a legal right to dismiss the person if suitable work cannot be found. The Occupational Safety Act requires that the use of technical aids and the special needs of disabled people must be taken into account. Employment subsidies include support to the employer costs and support to the unemployed person for self-employment and on-the-job training. A subsidy for a disabled person can be paid to an employer for a maximum of two years. The amount of subsidy varies for each individual placed through the employment services.	No	√	No

		The Penal Code prohibits discrimination on, among others areas, health grounds. An employer discriminating against someone on health grounds can be subject to a fine or imprisonment for at most six months.			
Spain	The Constitution refers explicitly to the rights of people with physical, mental or sensory disabilities to work, to complete self-fulfilment and to full social integration. Also the Workers Statute states that no-one may be discriminated against on grounds of physical, mental or sensory disabilities, provided they are able to perform the work or job concerned.	Legislation passed in 1982 sets out the state's responsibilities for prevention of disability, education, rehabilitation, social security and guaranteed minimum economic and social rights, as well as for vocational training and integration at work.

A Royal Decree regulates the reinstatement of disabled workers once they have completed the relevant rehabilitation process. If a worker suffers a permanent partial disability, he or she is entitled to re-employment in the same firm, either in the same job with a similar wage, if outputs remain normal, or in a job adapted to residual capacity with a wage drop of no more than 25 percent. Pay cannot be less than the minimum statutory basic wage, if the worker is employed full time. If the worker regains full capacity, the employer is required to reinstate him/her in the original job. A trial period of adjustment can be agreed for no longer than six months.

The quota system, introduced in 1983, requires public and private employers with more than 50 workers to reserve two per cent of their jobs for registered disabled people, whose capacity for work is reduced by one third or more. For Government employees, the quota is set at three per cent, but research has concluded that the quota for civil servants is rarely met and that private companies have little or no compunction about not meeting the lower quota. An additional proposal would give companies the alternative of donating to a Fund to encourage the inclusion of disabled workers in open employment. | | | |
| Sweden | No specific provisions | The Disability Discrimination Act, 1995 makes it unlawful to discriminate against disabled people in connection with employment, the provision of goods and services and buying or | √ | √ | √ |

| | | renting land or property. The Act protects disabled people from discrimination by employers (with 15 or more employees) by making it unlawful for such an employer to treat a disabled person less favourably than he would treat other people. It requires employers to make reasonable adjustments to arrangements and physical features of premises which place a disabled person at a substantial disadvantage in comparison with non-disabled persons so as to prevent the arrangement or physical feature from having that effect.

On 1 October 1999 new duties came into force requiring service providers to make reasonable adjustments, such as providing extra help, where the services are impossible or unreasonably difficult for disabled people to use. From 2004, service providers will also have to make reasonable adjustments to the physical features of their premises to overcome physical barriers to access. A disabled person who has experienced less favourable treatment or who believes that a reasonable adjustment should have been made has the right to take civil proceedings against the service provider concerned.

In 2000 a Disability Rights Commission was establishment to help disabled people enforce their rights and to provide advice for employers and service providers on their duties under the Disability Discrimination Act. | | | |
|---|---|---|---|---|---|
| UK | The UK has an "unwritten" Constitution. The Human Rights Act 1998, gives effect to the rights under the European Convention of Human Rights, including Article 14 prohibition of discrimination. | The Disability Discrimination Act, 1995 makes it unlawful to discriminate against disabled people in connection with employment, the provision of goods and services and buying or renting land or property. The Act protects disabled people from discrimination by employers (with 15 or more employees) by making it unlawful for such an employer to treat a disabled person less favourably than he would treat other people. It requires employers to make reasonable adjustments to arrangements and physical features of premises which place a disabled person at a substantial disadvantage in comparison with non-disabled persons | No | √ | √ |

| | | so as to prevent the arrangement or physical feature from having that effect.

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APPENDIX 6: UK AUDIT COMMISSION. CHECKLIST OF ISSUES TO CONSIDER IN MEETING THE EQUALITY STANDARD IN LOCAL GOVERNMENT

The Equality Standard exists at five levels:

Level 1: Commitment to a Comprehensive Equality Policy
Level 2: Assessment and Consultation
Level 3: Setting equality objectives and targets
Level 4: Information systems and monitoring against targets
Level 5: Achieving and reviewing outcomes

The UK's Audit Commission report *Learning from Audit, Inspection and Research* suggests that there are five critical factors for improving equality and diversity:

- commitment– understanding the concept, owning and leading the work at the highest levels, and committing adequate resources
- involving users– consulting the actual and potential users of services about their needs and requirements
- mainstreaming equality and diversity– integrating equality and diversity into day-to-day work, and translating policy into practice
- monitoring performance data– ensuring that data gathering and analysis on equality and diversity is part of core performance monitoring systems
- sustainability– continuously keeping up the momentum to counter discrimination and promote diversity, reviewing performance and setting new targets

The following checklists have been developed to help organisations move through the levels.

CHECKLIST 1 Commitment
- Do we have a comprehensive policy in place on equality and diversity?
- Do we have a vision for equality and diversity including tangible outcomes for users and staff?
- Do all staff have simple, brief, written definitions of equality and diversity?
- Do all staff have access to equality and diversity training?
- Do staff understand that equality and diversity is the responsibility of all staff?
- Are our senior managers leading by example?
- Are members committed and are they involved, for example, in the scrutiny of equalities?
- Are equality and diversity seen as part of the day job, and not as an add-on initiative?
- Are equality and diversity understood as being important, even when ethnic minority group numbers are small?
- Are equality and diversity defined as being about valuing everyone?
- Are staff concerns about equality and diversity heard and openly addressed?
- Are the best methods of effecting change being used?
- Are equality and diversity considered during budget planning processes?
- Have we conducted a diversity audit?
- Have the likely costs and benefits of any actions and modifications been assessed?
- Have any 'quick wins' been identified?

CHECKLIST 2 Involving users

- Do we know what communities we serve? Do we measure key groups?
- Are our users representative?
- Do we ensure that our user focus groups are representative?
- Is consultation and monitoring centrally driven? Is it effective?
- Do we listen to, and act on, user concerns, and feedback on what we are taking forward and why?
- Do we acknowledge that some groups may be suspicious of new initiatives?
- Have we made efforts to explain new initiatives to users, and have we been clear about what they can expect?
- What do we do to break down barriers between community groups?
- Are we involving local people in developing our equality and diversity strategies?

CHECKLIST 3 Mainstreaming equality and diversity
- Have we evaluated how to serve women, disabled people and black and ethnic minority communities?
- Is responsibility for delivering equality and diversity centralised or devolved to departments? Is our choice proving to be effective? Have we considered the possible options?
- Do we have equality and diversity 'champions'? Where are they located? Is this effective?
- Do we have sufficient expertise on equalities in-house, or do we need to find another way to access this?
- Are we developing a critical mass of knowledgeable and skilled staff that can help to mainstream equality and diversity? What more could we do?
- Do we have an equality and diversity strategy? Are staff involved in developing it?
- Do we have an equality and diversity action plan? Are staff involved in developing it?
- Are equality and diversity built into our vision, and all of our processes including best value reviews?
- Do we regularly communicate information on equality and diversity to our staff?

CHECKLIST 4 Monitoring performance data
- Have we considered which data would be useful to our decision-making processes?
- Have we considered monitoring service delivery BVPIs by gender, ethnicity and disability where appropriate?
- Do we have staff and systems that can capture these data?
- Do we explain clearly to people the reason why we are requesting this information?
- Once captured, do we analyse the data? Are our staff trained to do this?
- How do we feedback our performance to staff and users?
- Do we use performance data to inform changes to what we do?
- Have we set clear targets that staff understand?

CHECKLIST 5 Sustainability over time
- How can we sustain our equality and diversity efforts over time?
- How can we ensure that equality and diversity maintains its profile?
- Do we have both short- and longer-term targets in place to promote a rolling programme of improvement?
- Have we aligned sufficient financial resources and staff to ensure the longevity of our equality and diversity programme?
- Are our initiatives timely, reflecting previous progress and current needs?