



# Illness, disability and social inclusion



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**Author:** Stefanos Grammenos

**Research institute:** Centre for European Social and Economic Policy (CESEP), Brussels

**Stefanos Grammenos** is Director of CESEP. An economist by profession, he has written several reports on European policy concerning the socio-economic integration of minority groups.

**Foundation project:** Illness and inclusion

**Research management:** Philippe Bronchain and Robert Anderson



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European Foundation for the Improvement of Living and Working Conditions  
Wyattville Road  
Loughlinstown  
Dublin 18  
Ireland  
Telephone: (+353 1) 204 31 00  
Fax: (+353 1) 282 42 09 / 282 64 56  
E-mail: [postmaster@eurofound.eu.int](mailto:postmaster@eurofound.eu.int)  
**[www.eurofound.eu.int](http://www.eurofound.eu.int)**

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# Foreword

In recent years the Foundation has devoted particular attention to examining measures for the prevention of ill-health and implementing workplace strategies to maintain and improve general health. Research has looked at various aspects of disability and at issues regarding both social inclusion and disadvantaged groups and access to employment and has focused on ways to promote social inclusion.

Specific consideration of the links between illness and inclusion, however, has not taken place. It is against this background that the Foundation decided to launch a study with the objective of examining how to drive forward the social inclusion of people with illnesses – a broad reference to chronic (physical or mental) illness and disability. The project highlighted in this publication is, therefore, essentially a new research direction, linking different interests of the Foundation.

In concrete terms, the project aims to address the values and concepts underlying this issue and to examine how those concepts are being implemented. It reviews the nature and scale of the problems facing different groups with a chronic illness or disability. It also aims to identify policy initiatives in employment, education, housing, transport and other areas which facilitate social and economic integration, particularly where there are efforts towards more integrated policies or more comprehensive services. The report concludes with concrete proposals for future action in this domain.

For the European Union and the Member States, the social inclusion of people with a disability or illness is crucial in order to reach the objectives of the Lisbon summit of full employment and cohesion and to promote a more inclusive society. We are thus particularly pleased to make this report available during the European Year of People with Disabilities.

Raymond-Pierre Bodin  
*Director*

Willy Buschak  
*Deputy Director*



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## Acronyms and abbreviations used in the report

ADA:	Americans with Disabilities Act
ADL:	Activities of Daily Living
Council:	Council of the European Union
DDA:	Disability Discrimination Act
ECHP:	European Community Household Panel
EDEF:	European Disability Forum
EU:	European Union
Foundation:	European Foundation for the Improvement of Living and Working Conditions
ICIDH:	International Classification of Impairments, Disabilities and Handicaps
ILO:	International Labour Office
OECD:	Organisation for Economic Co-operation and Development
WHO:	World Health Organisation

# Introduction

The development of policies and the delivery of services to promote the social inclusion of people with a chronic illness (physical or mental) or disability are receiving increasing attention, particularly with respect to their integration into working life.

For people with a disability or chronic illness and for their relatives, social inclusion is a personal but essential issue. At a European and national level, the social inclusion of people with a disability or illness is crucial in order to reach the objectives of the Lisbon summit and to promote a more inclusive society.

However, the effects of illness and disability are not sufficiently addressed in key policy areas such as education, employment, care or housing. Chronic illness, and especially mental illness, remains very much a hidden issue. Discussion about disability tends to get stuck on the issue of rights, where there is a lacklustre consensus, but fails to move into the area of active policy implementation. As a result, the disadvantages for people with disabilities or illness do not really change: they tend to be marginalised, even stigmatised, and feel isolated from many parts of social and public policy as well as the labour market.

This group also tends to experience an accumulation of problems. With less possibility of getting or keeping a job, many are deprived of adequate income. Furthermore, the public sector tends to tackle the issue from one perspective (public health) or another (social affairs) and usually not in a comprehensive way (physical illness but not mental illness; social assistance but not inclusion; benefits but not activation). There is a lack of critical assessment about how the policies work and what could be the best allocation of resources.

Against this background, the Foundation decided to enter the debate. In its work programme 2001-2004, the Foundation's Administrative Board decided to give particular attention to people with illness and disabilities. And it is no coincidence that this important report is being published in 2003, the European Year of People with Disabilities. The convergence of efforts at European and national levels demonstrates clearly the extensive and essential character of this issue.

This report is intended to give an overview of key issues in order to fuel the debate and increase the attention devoted to people with disabilities. It is also an opportunity to extend the traditional scope of interest by placing a specific focus not only on people with disabilities, but also on people with chronic illness, particularly those of working age.

This initiative relates naturally to the priorities of both national governments and European Union institutions in addressing the participation of people with disabilities in working life. However, the report makes the point that exclusion from labour market participation for health reasons is a result of many factors, demanding action in many policy areas. It also suggests that social inclusion cannot be reduced to the issue of integration into employment.

The report is divided into two main parts. The first part outlines the nature and scale of the problems facing people with illness and their families, with a special focus on the social determinants of health and disability, social exclusion, barriers to participation and independent living and labour problems. The second part presents, in a critical way, the main policies adopted by the European Union and the Member States, detailing the key issues and setting out the nature

of the debate before drawing out conclusions and recommendations for future action. A comprehensive glossary clarifies the key concepts, showing, where relevant, the different interpretations of the same term and the context in which they are used. The aim is to provide users and readers with a clear understanding of the concepts and their relationship to each other.

# Part 1

## Overview of main issues

Part 1 presents a critical overview of different issues. This part aims to clarify the problems and provide a certain number of instruments for a critical analysis. Part 2 presents the different policies aiming to solve the problems raised in this part. Technical terms have for the most part not been used in order to ensure that the text is accessible to a wide public. However, interested readers will find the relevant references to follow the reasoning that lies behind certain statements that appear 'self-evident' but in reality are based on numerous assumptions.

At the beginning of Part 1 basic questions concerning people with illnesses or disabilities are addressed: what are their main characteristics and what are the determinant socio-economic factors. The section continues with a presentation of the main problems encountered by people with an illness or disability during their lives: social exclusion, poverty, different barriers in participating in social and economic life and segregation. Finally, the section on labour market issues focuses on the major problems encountered by people with an illness or disability, such as inactivity, unemployment, wage discrimination, etc.

This part constitutes a tool for any policy-maker who wants to understand and assess the extent of the different dimensions governing the exclusion of people with a chronic illness or disability. The next part (Part 2) presents issues related to policy measures.



# Characteristics of people with a chronic illness or disability

## Population of people with illness or disability

### Statistical definitions

In recent years a considerable quantity of data has been produced. The chief sources for this are:

- the European Community Household Panel (ECHP),
- special surveys on impairments, disabilities and handicaps (e.g. Spain, France, Austria, Portugal and the United Kingdom),
- national health interview surveys.

Certain Member States use the International Classification of Impairments, Disabilities and Handicaps (ICIDH), but frequently definitions differ.

Only the European Community Household Panel (ECHP) has a common questionnaire centrally designed by Eurostat. This allows comparison across Member States that is not possible in other surveys and censuses. It does not exclude subjective wording and linguistic variations, but it does minimise the risk. The questions on health status and disability are:

Question 157: How is your health in general?  
Very good / good / fair / bad / very bad.

Question 158: Do you have any chronic physical or mental health problem, illness or disability?  
Yes / No.

Question 159: Are you hampered in your daily activities by this physical or mental health problem, illness or disability?  
Yes, severely / Yes, to some extent / No.

Similar questions are widely used in many European surveys and censuses (health interview surveys, for example). They rely on self-perception and self-assessment. Self-assessment raises the following problems (R. Burkhauser and M. Daly, 1998; J. Bound, 2001):

- self-evaluated health is a subjective measure that may not be comparable across respondents;
- the reported measures may not be independent from employment status, income level, etc.;
- respondents out of the labour force may mention health limitations to rationalise their behaviour;
- respondents may have a financial incentive to identify themselves as disabled, as early retirement benefits are often available only for those deemed incapable of work.

Subjective elements may generate measurement errors. For this reason it is preferable to present more objective measurements, for example based on a checklist, activities of daily living or

disabilities. Also, the subjective nature of self-reported health status may exaggerate its impact on economic variables.

Table 1 and Figure 1 present results for the EU Member States. For comparative purposes results from the USA have been included in the figure. The table presents the data for severe and moderate disability. It appears that about 15% of the working-age population are hampered in their daily activities by physical or mental health problems, illness or disability.

The table does not systematically show any statistically significant difference between men and women of working age in the EU. However, national differences are significant.

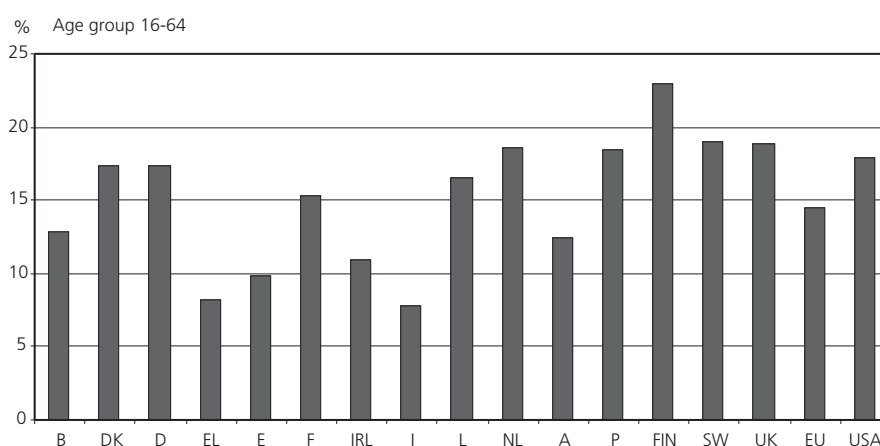
The estimation for the whole population provides a disability prevalence rate of about 17%<sup>1</sup>. This is close to previous estimations for people with impairments (S. Grammenos, 1995). In fact, as noted above, the definition is rather large and the terms used are closer to functional problems rather than significant limitations in daily activities. As explained below, the rate for the number of people with disabilities, following the International Classification of Impairments, Disabilities and Handicaps (ICIDH), ought to be smaller.

**Table 1 Percentage of working-age population (16-64) reporting chronic illness or disability**

	B	DK	D	EL	E	F	IRL	I	L	NL	A	P	FIN	UK	EU-14
<b>Severe</b>															
Men	5.0	4.6	5.2	3.5	3.6	6.0	2.7	2.1	4.6	4.7	3.1	6.7	6.7	6.4	<b>4.7</b>
Women	4.2	4.8	4.0	3.2	3.0	6.0	2.2	2.4	4.1	6.8	3.4	8.2	5.8	5.1	<b>4.3</b>
<b>Moderate</b>															
Men	7.9	10.1	12.4	4.2	6.2	8.8	8.1	5.4	12.9	11.4	10.1	9.9	15.0	11.6	<b>9.3</b>
Women	8.7	15.4	12.9	5.5	7.0	9.8	8.8	5.7	11.4	14.0	8.5	11.9	18.4	14.5	<b>10.6</b>

Source: Eurostat, 2001. Survey data.

**Figure 1 Persons with chronic illness and disability, EU and USA**



Source: Eurostat 2001, J. M. McNeil, 1994 and A. Bergeskog, 2001. Survey data.

<sup>1</sup> Estimation of a logistic function on aggregated national data provided by the ECHP. Application of the estimated rates, by age group, to the total EU population, 2000. The estimated function is: Prevalence rate =  $1 / (1 + \text{EXP}\{-\alpha + \beta * \text{age}\})$ .

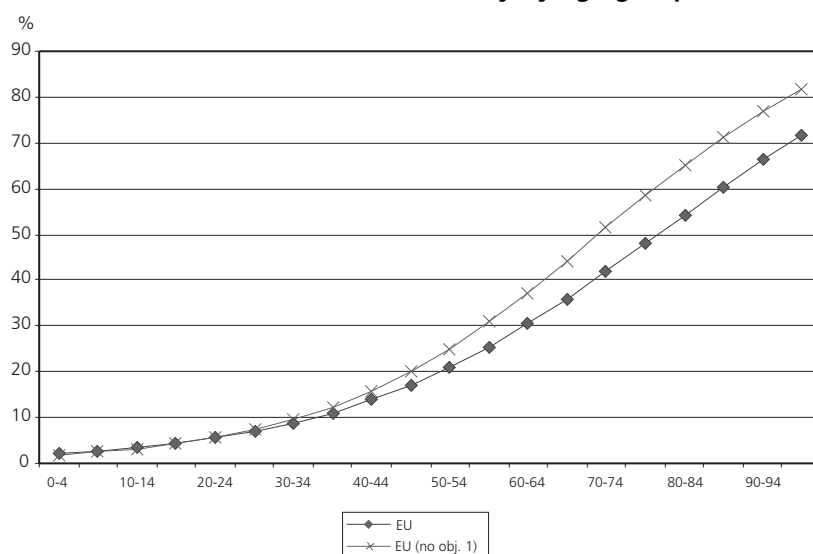
## Age

There is a large variation between Member States and a significantly lower rate in some Mediterranean countries (Greece, Spain and Italy). Econometric analysis<sup>2</sup> indicates that this is not the result of age composition. The analysis shows that two groups of countries can be distinguished. One group includes Objective 1 countries with a lower prevalence rate at all ages and a second group of countries with a significantly higher disability prevalence rate at all ages.

Finland has the highest rate, which might be attributed to a cohort effect, a low standard of living in Finland that lasted until the mid-1950s (K. Silventoinen and E. Lahelma, 2001).

Some authors have proposed cultural influences as one factor explaining the lower rate in Objective 1 countries; others have identified working and living conditions in post-industrial societies. However, high variability is also reported within individual Member States. For example, the UK Labour Force Survey, 2000, reports a national average rate of 18.8%, a minimum regional rate of 15.8% and a maximum regional rate of 23.9%. The differential between regional rates is relatively higher among older persons (F. Sly et al, 1999). Similar differences have been reported by many surveys (e.g. health survey in Belgium).

**Figure 2 Persons with a chronic illness or disability by age group in the EU**



Note: EU estimation includes all Member States (except Sweden). EU (no obj. 1) excludes Objective 1 countries and Finland. This estimation is very close to American data. The estimated function is:

$$\text{Prevalence rate} = 1 / (1 + \text{EXP}\{-(\alpha + \beta * \text{age})\}).$$

Source: Eurostat, 2001.

## Gender

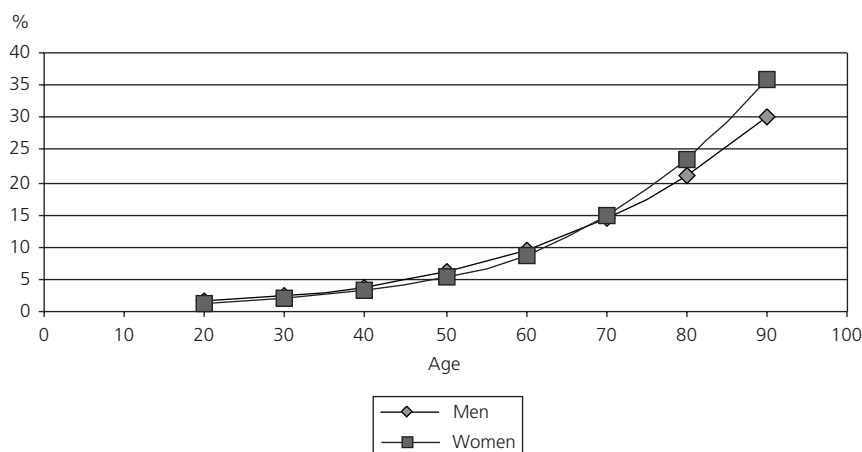
The life expectancy of women is higher than that of men. Consequently, a higher prevalence rate for women for the total population might be expected. In order to take into account this possible bias, it is necessary to compare the prevalence rate for each age group.

<sup>2</sup> Regressions of a logistic function on aggregated data by age group, using dummy variables for the country, testing both for constant and slope coefficient. The estimated function is: Prevalence rate = 1 / (1 + EXP{-( $\alpha + \beta * \text{age}$ )}. In general, very high R<sup>2</sup> is obtained.



The following figure indicates that there is no significant difference between men and women at least until their 60s. After this age the prevalence rate for women becomes higher than for men. The figure compares severe limitations in order to exclude moderate problems related to old age.

**Figure 3 Persons with a severe chronic illness or disability by sex and age in the EU, 1996.**



Source: Eurostat, 2001.

### Degree of disability

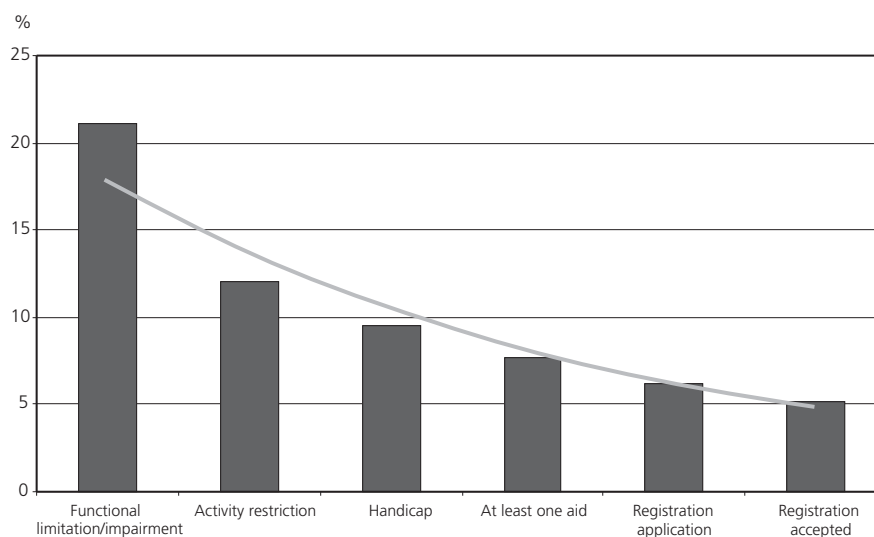
One important factor is the duration of disability. The term 'chronic' may be interpreted in different ways (a few months, one year, etc.). The estimation is very sensitive to this measure. Inclusion of short-term limitations may increase the disability rate sharply.

Another important distinction is the evaluation of what is 'severe' and 'moderate', linked to the degree of disability. Figure 4 presents the rate for France of people with disabilities according to different definitions. It indicates that a large number of people report a relatively slight problem. But the rate decreases as the definition comes closer to severe limitations. The figure shows also that the wording is important. The general term of at least one functional disability/impairment gives a much higher rate compared with the restrictive and non-neutral term 'handicap'. A recognised registered person with disabilities is the most restrictive definition and consequently the corresponding rate is the lowest.

Similar results are reported for US panel surveys (R. Haveman et al, 1995). For example, with people aged 19-64 the findings are:

- persons with poor health or a functional disability (difficulty in performing one or more activities of daily living, including both ADL and IADL): 19.6%
- persons with functional disabilities: 14.9%
- persons with fair or poor health: 11.8%
- persons with two or more functional disabilities: 6.9%.

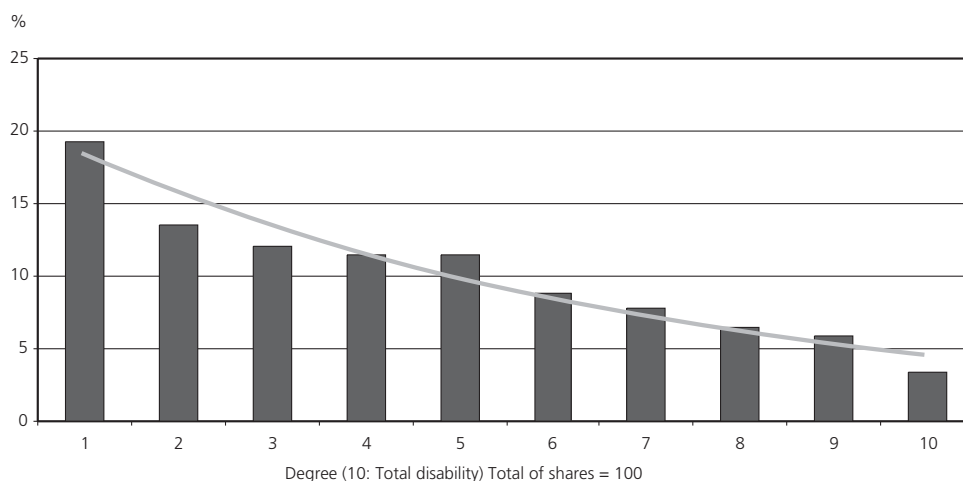
**Figure 4 Prevalence of disability according to different definitions in France**



Source: J. F. Ravaud et al, 2001. Survey data.

The distribution of disabilities in the United Kingdom leads to similar conclusions. Among people reporting disabilities a high proportion do not have a severe problem. The proportion decreases as the degree of disability increases (Figure 5).

**Figure 5 Distribution of persons with a chronic illness or disability by degree in the UK (restrictions in daily activities)**



Source: S. Grammenos, 1995. Survey data.

In conclusion, the data are not inconsistent. They simply need proper interpretation. Each term and definition provides an estimate useful for the elaboration of the relevant policy:

- a broad definition provides information relevant to the formulation of prevention policies;
- a strict definition (handicap, restrictions at work or in daily activities) provides information on the core group, which ought to be the priority for a policy of inclusion;
- severe problems help us identify people with long-term care or assistance needs.

## Work-limiting disabilities

'Limiting longstanding illness' is another concept used in many surveys: for example, the survey of living conditions in the Nordic countries, health interview surveys and the census in Belgium (K. Silventoinen and E. Lahelma, 2001; V. Lorant et al, 2002).

The screening question is: Do you have any longstanding illness, disability or infirmity?

Follow up question (if 'yes'): Does your illness or disability restrict your work or does it limit your daily activities (gainful employment, housework, schooling or studying)?

In general these surveys report a prevalence of disability, correcting for age, which is slightly higher compared with the European Community Household Panel (ECHP). In fact, the term 'longstanding' is broader than a 'chronic' state. Inclusion of very short durations is expected to increase sharply the reported prevalence rate.

The United Kingdom is the only country with a well developed tradition of questions on work-limiting disabilities. People whose health problems or disabilities are expected to last more than a year are asked the following question (F. Sly et al, 1999):

Does this health problem affect the kind of work that you might do?  
... or the amount of paid work that you might do?

If respondents fulfil either of these criteria they are defined as having a work-limiting disability. A similar question is used in the American Survey of Income and Programme Participation (SIPP) (J. M. McNeil, 1994). These surveys have been influential in shaping the European Labour Force Survey in its questions on the employment of persons with disabilities.

The reported measure may be different from the inability to carry out a specific task or job. In this latter case specific job requirements are taken into account. Disability is not simply a persistent abnormality or physiological function: it is based partly on a job's environment and partly on impairments and functional limitations (Haveman et al, 1995).

**Table 2 Persons with work-limiting disabilities (% of working-age population)**

	Finland 1996	Sweden 1998	Sweden 1994/95	UK 1994/5	UK 2000	France 1998/9	USA 1991/2
Work disability: Total	11	11	11	11.2	15.9	13.9	11.6
Men			10	-	16.3	13.6	11.7
Women			12	-	15.5	14.1	11.6
Disability	23	17	17	-	18.8	-	17.9
Survey	IDS	LFS	SLC	LFS	LFS	HID	SIPP

Note: SW: maximum rates for 1994/95. UK: 1994/95 and 2000 are not comparable.

Source: A. Bergeskov, 2001; J. M. McNeil, 1994; Sly et al, 1995; Socialstyrelsen, 1998; B. Twomey, 2001.

Some studies have revealed that non-workers systematically over-report the effects health conditions have on their ability to work (R. T. Riphahn and B. Kreider, 1997). Self-reporting seems to be influenced by labour market success and disability may be one of the socially acceptable reasons for men under the age of 65 withdrawing from the labour force. Consequently some researchers favour more objective measures of work capacity.

The Labour Force Survey 2002 included an ad hoc module on the employment of people with disabilities, which had three important aspects:

- work-limiting illness and disability,
- type of disability, and
- type of assistance required or provided at work.

This was the first attempt to collect comparable statistics at a European level on these issues. The analysis of the link between type of disability and type of aid will be important for the formulation of relevant policies.

### **Administrative definitions**

The provision of pensions, allowances and services related to chronic illness and disability require the definition of the conditions under which a person may claim a right to a benefit. In general, within a Member State, each service uses its own definition of chronic illness and disability. The different definitions that may be distinguished are related to:

- disability pensions: national social security systems often require a reduction in work capacity;
- disability allowances: social action often includes both medical and social criteria; and
- benefits related to independent living: the definition is broader and takes into account limitations in the activities of daily living.

In Part 2 national policies are presented in detail. Here, it is sufficient to look at the number of people receiving benefits related to chronic illness or disability.

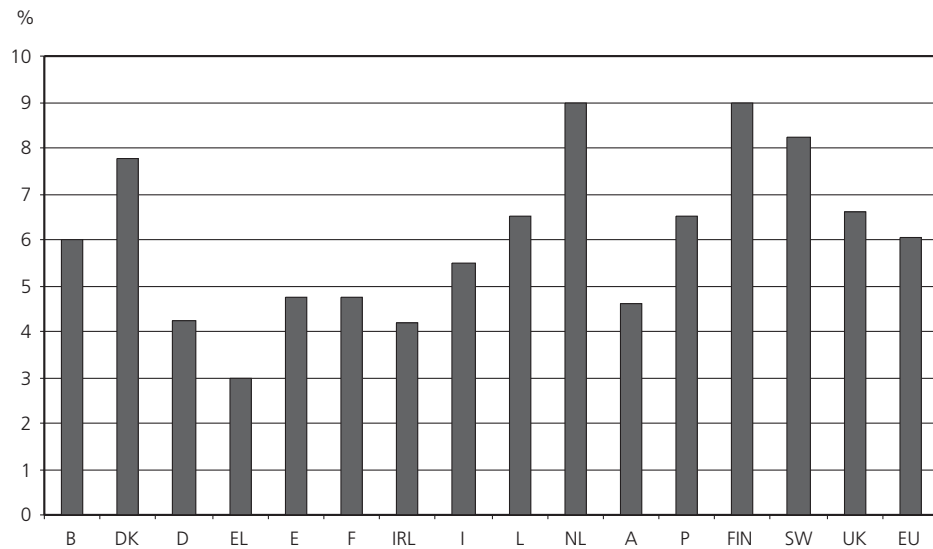
At the EU level the proportion of people of working age receiving a disability-related benefit amounts to 6%. The rate was about 5% in 1990 and increased to 6% in the early '90s. Restrictive policies stabilised the rate and decreased it in some countries where it was very high (e.g. the Netherlands and Sweden).

The ECHP (1996) and the following table both report 6% of people aged 20-64 as being in receipt of disability benefits at the European Union level.

The proportion of beneficiaries is small compared to the prevalence rates presented in the previous section. This means that an important number of people might incur expenses related to chronic illness and disability, which are not refunded by social security or social protection systems.

There is much variance across Member States and some countries (Germany, Greece, Spain, France, Ireland and Austria) have a significantly lower rate. A large number of people with chronic illness or disability could be excluded from any kind of financial benefit.

**Figure 6 Persons receiving a benefit related to chronic illness and disability, EU, 1999 (% of 20-64 age group)**



Source: OECD, 2002 and S. Grammenos, 1995 (for EL, IRL & L). The data for EL, IRL & L are not comparable with the remaining countries. Administrative data. The OECD data for the United Kingdom might overestimate the true numbers.

### The nature of illness and disability

Several surveys of illness and disability have been carried out in the Member States. Most of them are not comparable. In order to present a short summary of the situation, two countries with well established methods, conforming closely to international classifications, have been selected: Spain and the United Kingdom.

The following table presents the data for impairments and disabilities. Impairments are closely related to medical diagnosis. Musculo-skeletal problems are the most common impairments. This often leads to mobility problems so getting around is the main reported disability. Disabilities relate closely to classifications of activities of daily living, an index often used in surveys of the elderly.

The data for the United Kingdom on persons aged 16+ show higher rates because respondents may report more than one complaint and because they include elderly people.

The UK data do not show significant differences between men and women, but this is not the rule for other surveys. Mobility problems appear to be important for all ages. There are significant differences across ages for personal care and housework. The prevalence rate of these limitations is much higher for elderly people.

**Table 3 Nature of chronic illness and disability (percentage)**

	Impairment			Disability		
	Spain	UK			Spain	UK
	Age	Age	Adults		Age	Adults
	6-64	16-64	(16+)		6-64	(16+)
	Total	Total	Total		Total	Total
<i>Type of impairment</i>	Main	Main	Complaint	<i>Type of disability</i>	Main	Complaint
Mental	17	13	13	Seeing	6	24
Ocular	15	2	22	Hearing	5	41
Aural	16	2	38	Communicating	4	17
Language	1	...	...	Learning, intellectual	7	21
Musculo-skeletal	33	36	46	Getting around	32	69
Nervous system	8	36	13	Using arms and hands	12	19-27
Visceral	7		20-30	Caring for oneself & housework	27	37
Other	3	12	6	Relations with others	6	20
Total	100	100	(100)	Total	100	(100)

Note: UK: Adults (16+). Percentages do not add to 100 as some people have more than one complaint. The rates are higher compared with Spain because they include persons over 65. Data to be interpreted with caution as reported surveys use different definitions and classifications of illness and disability.

Source: INE, 2001; B. Twomey, 2001 and S. Grammenos, 1995. Survey data.

The group of people with illnesses or disabilities is not a homogeneous one. Differences in the nature of their disabilities reveal differences in the type of assistance needed. Consequently the nature of disabilities is an important factor for the elaboration of policies.

### From sickness to dependency: a life cycle approach

People often think of illnesses and disabilities as if they were the result of congenital events. Figure 2 showed that illness and disability are not things acquired at birth, but in the course of life. They are life events that could be avoided or delayed in the perspective of a life cycle (e.g. in the case of old age problems).

The rate of chronic illness or disability among the young (less than 20 years old) is no higher than 5% of their age group. For young people the rate of progression is very slow. It might be supposed that educational issues are the dominant ones for the young. But this is also the age when attitudes and lifestyle preferences are formed. Certain behaviour patterns might involve the risk of illness or disability and this raises the question of prevention. Of course an unfavourable environment may by itself be an adverse factor.

Congenital and obstetric reasons account in general for 10% of all chronic illnesses and disabilities (S. Grammenos, 1995). Sickness is the major contributor during active life, and to a lesser extent accidents. Accidents at work and professional diseases play a significant role and become the main reasons for impairments and disabilities for people aged 45 to 54 (ISP, 2002). Causes related to old age are dominant at a later stage.

Sickness, risky lifestyles, work accidents and socio-economic factors either separately or in combination generate a process where the rate of chronic illness and disability moves progressively

from 5% among young people to 40% at retirement age. Chronic illness often seems to be the result of the accumulation of disadvantage throughout life. In fact people often report that disability is the result of sickness or has appeared gradually. The accumulation of moderate illness and disability gradually generates severe cases. This idea has been supported by many surveys (for example, the European Community Household Panel), which show that the proportion of severe illnesses and disabilities increases – relative to moderate cases – with age.

Old age and the related issue of care dependency raise the question of relevant policies for home help and independent living. Home help services imply service and personal care in the home. Service tasks include personal activities of daily living (such as bathing, dressing and feeding oneself) and instrumental ones (such as cooking, shopping and housekeeping). Furthermore home nursing often requires specialised medical care several times a day.

For Europeans a high level of protection against the risk of illness and dependency is a vital asset. The share of the total population older than 65 is expected to increase – from 16.1% in 2000 to 22% by 2025 (European commission, COM (2001)). This trend is likely to have major consequences for social protection systems.

People live longer and this increases the risk of long-term care needs. Developments in medical technology may reduce the pressure to increase spending on health care and long-term care. Nevertheless the viability of existing systems has been questioned and new instruments have been adopted (e.g. long-term insurance in Germany and Belgium (Flanders)). The aim is to maintain high living standards at a time of life when income decreases and expenses related to medical and care needs increase. Some elderly require long-term care. This presents a special challenge in terms of financing and the necessary adjustments on the supply side, especially for long-term institutional care (European Commission, COM (2001)).

The following tables show there are about 25 million adults in the European Union with a severe chronic illness or a disability. It is estimated that about 15 million adults need the help of a third person to carry out the elementary tasks of a normal life (bathing, dressing, feeding oneself, cooking, shopping and housekeeping).

**Table 4 Number of persons with a chronic sickness or disability in the EU**

Age group	Less than 20 years	20 to 60 years	60 + years	Total
Number	2,800,000	27,800,000	29,400,000	60,000,000
%	5%	46%	49%	100%

Source: own estimations using ECHP data (Eurostat, 2001).

**Table 5 Number of adult persons with a severe chronic sickness or disability in the EU**

Age group	–	20 to 60 years	60 + years	Total
Number	–	10,000,000	15,000,000	25,000,000
%	–	40%	60%	100%

Source: own estimations using ECHP data (Eurostat, 2001).

Recognition of chronic illness and disability designation often involves a long process, starting with absence from work due to sickness and ending in the recognition of a permanent disability status. The process begins with strictly medical factors, to which social factors are added during its course, notably when decisions are being taken about the granting of financial benefits.

In addition, repeated events (sickness, accidents etc.) during adult life accumulate and generate the need for long-term care of the elderly. This does not mean that chronic illness and disability among the elderly is merely a consequence of chronological age. The influence of income, education, lifestyles and work on health will be discussed in the next chapter. Increasing the extent of disability-free life expectancy requires an active policy of prevention at all ages, but especially during the economically active period.

Dutch longitudinal data reveal that increased work effort eventually (after 25 years) leads to a deterioration of health (M. Lindeboom and M. Kerkofs, 2002). This finding suggests that pension and social security reforms aimed at increasing rates of labour force participation among older people may have an adverse effect on their health. So policies aiming to increase the age of retirement ought to involve health impact assessments.

Improvements in living conditions and new medical technologies reduce illness and disability prevalence rates at every age, but have a relatively greater impact on the elderly. In terms of Figure 2 this is translated into a shift of the curve, which is greater with increasing age. In other words the rate of progression of chronic illness and disability is decreasing over time, and the number of quality-adjusted years is increasing. Chronic illness and disability tend to occur at an increasingly greater age with each generation.





# Social determinants of health and disability

# 2

## **Economic and social factors**

The Treaty stipulates that the objective of ensuring a high level of human health protection must be incorporated in the definition and implementation of all Community policies and activities. Socio-economic inequalities in morbidity and disability are an important public health problem in the European Union. A large number of studies have tried to identify the main determinants of health, but there is still an extensive debate taking place on the importance of each factor and on how they interrelate.

## **Income and health**

Recent studies report a positive correlation between income and health. At an international level poor countries tend to have worse health outcomes than better-off countries. Within countries poor people have worse health outcomes than wealthier people. But researchers do not agree on the direction of causality. A. Wagstaff (2002) proposes that the coincidence of poverty and ill health reflects causality running in both directions. Illness has a substantial impact on household income, as illness means loss of income and high health care costs. But poverty and low income also cause ill health. Poor people are thus caught in a vicious circle: poverty breeds ill health and ill health maintains poverty. Furthermore, he claims that socio-economic inequalities in health seem to be widening rather than narrowing. This raises the question of the efficacy of health services.

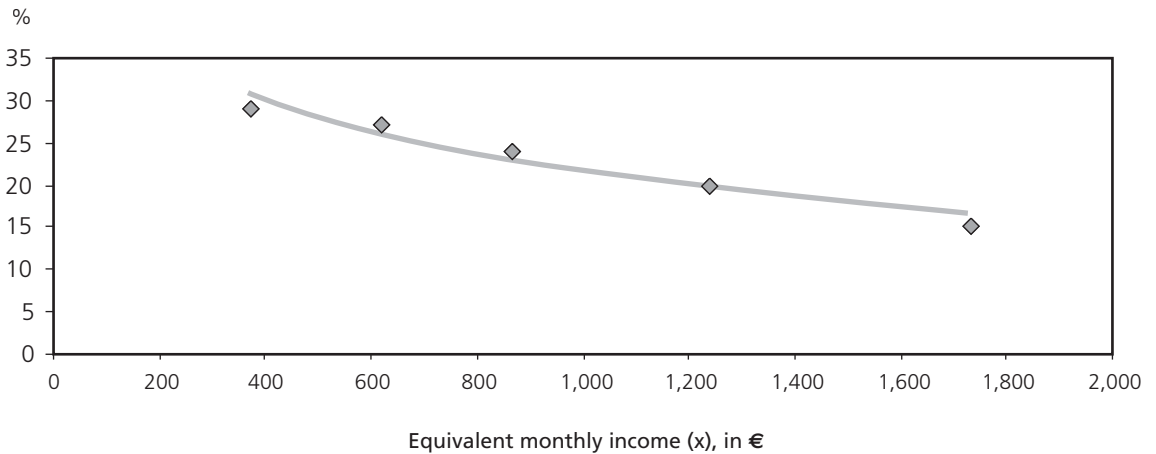
It is difficult to assess the direction of a true causal relationship between income and health. On the one hand individuals with higher incomes may have better access to health care services and so can prevent chronic illness and disability. On the other hand health problems may affect the individual's productivity and, therefore, earnings. Medical expenses further reduce available income.

Some studies (e.g. A. Wagstaff, 2002) find that the poor tend to use health services more than the better off. So they conclude that increasing health inequality is the result of inadequate services. Also Bidani et al (1997) find that differences in public health spending tend to matter more to the poor. But others (e.g. Van Doorslaer et al, 2001) present more mixed results. They find that people with higher income make more use of specialists' services than expected on the basis of predicted needs, both in Belgium and the Netherlands. In addition the poor tend to use medical services for cure while the rich use them for prevention. For example, poor households in Belgium tend to postpone care because of financial constraints (ISP, 1998). Conversely, expenditure on self-medication, prescription charges, massage and dentures in Germany rises with increasing household income (Federal Statistical Office, 1998).

Kakwani et al (1997) use two widely available indicators of ill health: chronic illness and self-assessed health. The stratifying variable is pre-tax household income. They divide the sample into income deciles. In general the lower deciles suffer somewhat higher levels of ill health than the higher deciles. The results indicate that even after taking into account the demographic structure of the sample, inequalities in health favour the better off.

Smith (1999) finds that both total household income and wealth have statistically significant positive effects on self-reported (good) health status. The relationship is non-linear with effects decaying across the income or wealth distribution – strongest among the poor and weaker among the affluent. The results for Belgium presented in the following figure support this statement.

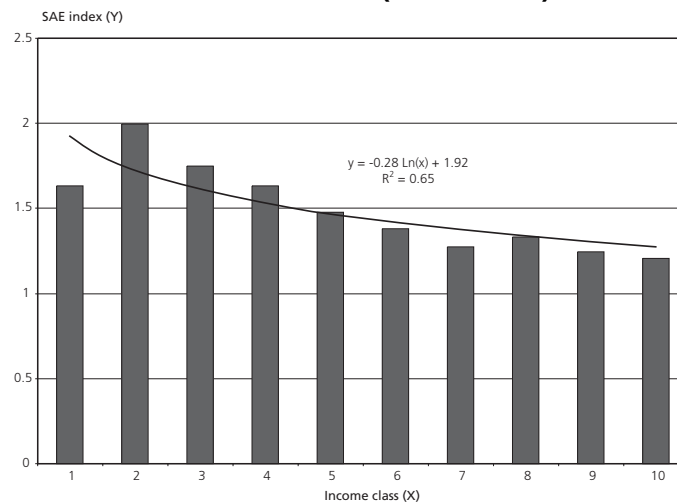
**Figure 7 Less good self-rated health according to equivalent income (Belgium)**  
 % of persons with 'fair to very bad' self-rated health



Source: F. Louckx et al, 2001.

Swedish data indicate that a lower socio-economic position not only goes with a higher prevalence of long-term illness but also with a higher degree of discomfort and suffering. The effect of illness on employment is also stronger in lower than in higher socio-economic groups, but this interaction seems to be much stronger in some countries (e.g. Britain) than in others (e.g. Sweden) (Lindholm et al, 2002)<sup>3</sup>.

**Figure 8 Self-assessed health and income class (Netherlands)**



Source: N. Kakwani et al, 1997.

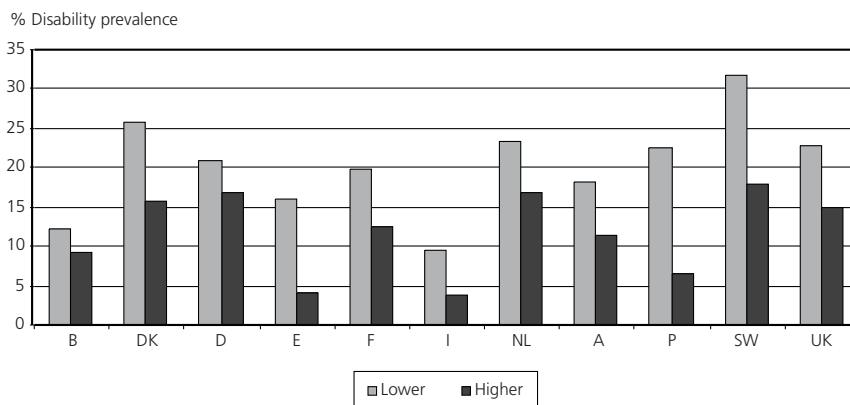
<sup>3</sup> Studies concerning both mortality and morbidity have shown that both relative and absolute health inequalities tend to be wider in the Nordic countries than in southern European countries (K. Silventoinen et al, 2002). This has been regarded as unexpected since the Nordic countries are usually considered as egalitarian societies.

Inequality in self-assessed health does not seem to be significantly associated with total health care expenditure per capita or gross domestic product per capita in nine OECD countries (A. Wagstaff, 2002). However, health inequality was positively and significantly associated with income inequality (A. Wagstaff, 2002; B. Bidani and M. Ravallion, 1997). But differences in health outcomes cannot be explained simply by the absolute deprivation associated with low income (e.g. lack of adequate health, education, housing etc.). The degree of relative deprivation within a society also matters.

**Education, lifestyles and health**

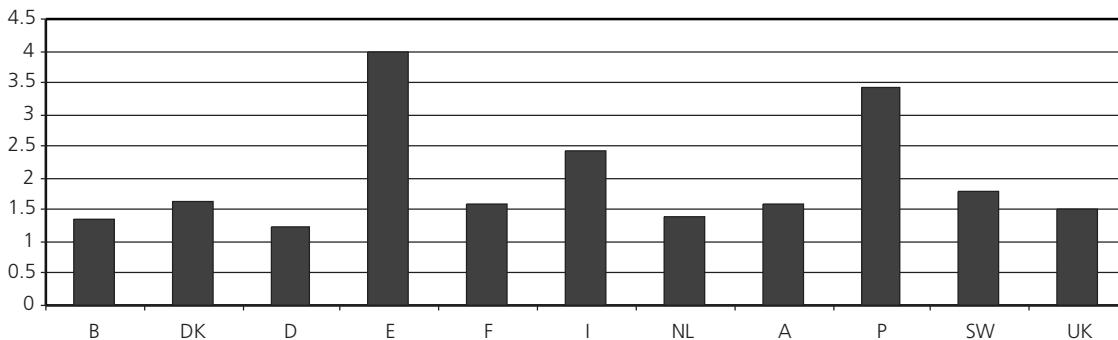
One major problem, encountered in different studies, is the presence of collinearity between education, income and socio-economic status. Higher education for some means better working conditions, for others healthy attitudes and behaviour, and finally for others it means higher income. In the first case, policy ought to focus on working conditions, in the second on preventing risky behaviour and in the last on medical care. So it is interesting to disentangle the different factors and measure the relative contribution of each element.

**Figure 9 Relation between illness/disability and level of education**



Source: OECD, 2002.

**Figure 10 Disability and educational inequality**  
(Ratio of disability rate of lower educated persons to higher educated persons)



Source: OECD, 2002. Survey data.

Higher: second secondary + tertiary; lower: less second secondary + still at school

The less well-to-do seem to have a stronger pattern of deleterious personal behaviour. Incidence of illness and death are particularly high among the lower social classes. Welfare recipients in Germany register twice as many illnesses or injuries due to accidents. People with lower income also smoke more frequently, are less active and are more often overweight than people with a higher income (Federal Statistical Office, 1998). This, combined with low income and expensive care costs, may generate an adverse process leading to chronic illness and disability.

### **Employment status and health**

Limiting, long-standing illness seems to have stronger adverse social and economic effects on manual workers. In fact manual jobs are less flexible compared with jobs held by more qualified people. This might lead more manual workers into unemployment compared with non-manual workers. Illness might also involve much greater adverse effects on their income and resources compared with wealthier, more qualified people.

Swedish and Finnish data show that the risk of adverse social consequences for people with limiting, longstanding illness is greater among manual workers than among non-manual workers. Similarly, blue-collar workers in Norway have a higher incidence of disability (Lindholm et al, 2001).

O. Rahkonen et al (2002) investigated the relationship between income and health in Finland. They especially looked at whether employment status, educational attainment, and occupational class – that is factors that are likely to affect income – had a similar impact on the relationship between income and health. They found that the relationship between income and health is strongly attenuated when employment status, education and social class are adjusted for. They concluded that a high proportion of income inequalities in health are associated with employment status and other preceding indicators of social status rather than with factors directly related to poverty. This implies that elimination of income inequalities will not eradicate social inequalities in health.

This view has been confirmed by the so-called ‘Whitehall studies’ of British civil servants. The first was conducted in 1967 and found a steep inverse relationship between employment grade and poor health outcomes (J. P. Smith, 1999). The sample was mainly composed of office workers with stable employment, so it was surprising to find such a steep relationship between socio-economic status (employment grade) and health. The second survey carried out in 1985-88, confirmed the results of the first one. The principal hypothesis was that psychosocial factors, such as work-related stress, played a dominant role. Monotonous work, with little control over the job, was a factor often reported in this context.

This further strengthens the argument that it is not only absolute deprivation that matters in industrialised countries, but also the relative position of the individual in society. Social protection schemes might have provided basic material needs in most European countries, but they have not improved social cohesion, in the sense of reducing inequalities. Smith (1999) puts forward the hypothesis that societies that place a high value on caring for one another and less on individualism are healthier ones. This might explain why some studies report lower health inequality in Mediterranean countries.

### **Job insecurity and health**

A number of studies find that perceived job insecurity has significant adverse effects on self-reported psychological and physical health outcomes.

A study by the Foundation offers some evidence that job insecurity leads to worse self-rated physical health and an increase in some clinical symptoms (European Foundation for the Improvement of Living and Working Conditions, 1999a). Ferrie et al (2002) use data on British civil servants and find that the loss of job security has adverse effects on self-reported health and minor psychiatric morbidity, which are not completely reversed by removal of the threat to jobs.

On the other hand C. Lindholm et al (2001), studying a cohort of the Swedish Survey of Living Conditions, maintains that ill health leads to high mobility in and out of employment, which in turn increases the risk of economic inactivity and social exclusion. They conclude that in order to reduce socio-economic inequalities as a consequences of illness, social policy should increase the chances of manual workers with long-standing illness remaining in work. This does not necessarily mean remaining their original jobs, as this could damage their health further.

There is a broad consensus that unemployment leads to a significant deterioration in reported well-being (Shields et al, 2001). Empirical studies report that unemployment affects:

- life satisfaction in the German panel data, and
- symptoms of psychological distress in the British panel data.

The psychological cost of unemployment seems to be higher for men than for women. It is also greater for younger workers than older ones. The use of panel data is important since it makes it possible to test causality running from unemployment to mental health.

It is interesting to note that social norms could play an important role. Unemployment has a lower psychological price in areas with high unemployment rates, and the stigma of unemployment is greater in low unemployment areas.

### **Social norms and health**

As was noted above, unemployment has a psychological cost and an associated stigma that may affect mental health, notably through stress and low self-esteem.

Baldwin et al (1993) found that employment participation affected reported disability in two ways:

- The direct effect: this is expected to be negative. People who hold jobs are not subject to social pressure and so do not claim disability status.
- The indirect effect: employment participation has an ambiguous effect on true disability. On the one hand the stress and physical demands of working may cause a person's disability status to deteriorate. On the other hand the lack of activity associated with non-participation could also cause a disability to worsen.

Several researchers have argued that males face more social pressure than females to justify non-participation or unemployment. Men who feel embarrassed about or ashamed of not working may

report an illness or a disability as a socially acceptable reason for non-participation. Women not participating in the labour market may put forward domestic responsibilities as the reason.

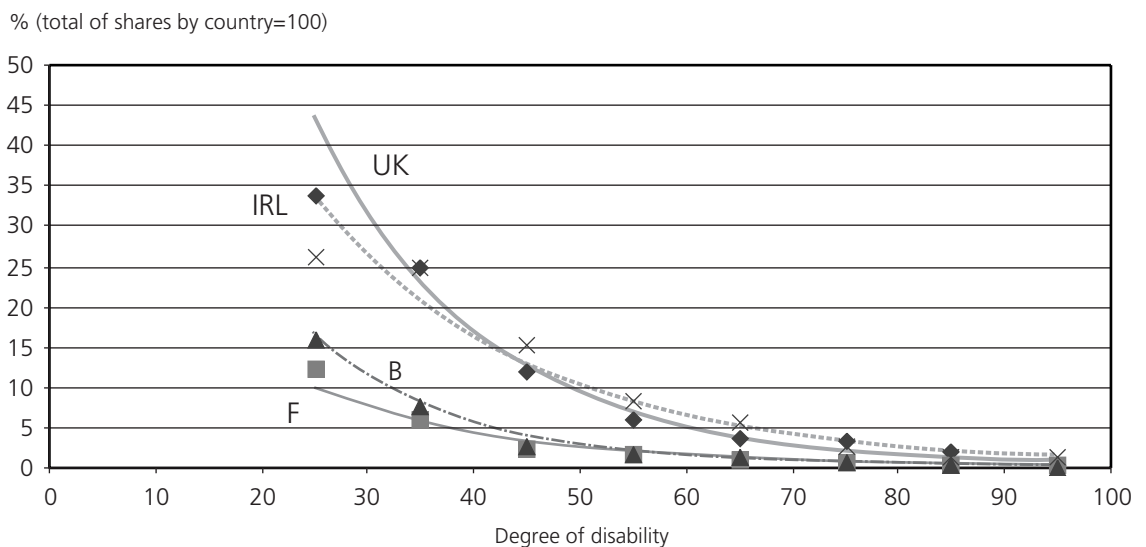
### Work accidents and working conditions

In discussing the socio-economic determinants of health and disability, it was noted that blue-collar workers have a higher incidence of disability. This raises the question of the contribution of work accidents and occupational diseases to the rate of chronic illness and disability. There is an increase in the number of declarations of occupational diseases in Germany, France, Denmark, and Portugal, but a reduction in Sweden, Italy, Austria, Belgium and Finland (D. De Brucq, 2001). However, this could be the result of cyclical fluctuations as levels of production increased in the late 1990s.

A general tendency towards fewer recognised work accidents and occupational diseases can be observed. But this could reflect a restrictive policy and a consequent increase in minimum requirements for the granting of benefits. Recent national policies to restrict access to disability pensions could reduce sharply the number of recognised work accidents and occupational diseases. The following graph indicates that most declarations concern work accidents with a relatively small degree of severity. Most relate to musculo-skeletal problems.

The minimum invalidity rate required for compensation is very low. It is only 1% in some Member States (Belgium, France, Luxembourg, Portugal). If it is less than 10% to 20% (depending on the country), this often gives the right to once-and-for-all compensation. If the work reduction is more than 20%, it generally gives the right to a work accident pension.

**Figure 11 Distribution of recognised industrial accidents by degree of disability**



Source: S. Grammenos, 1995.

To get some idea of the contribution of work accidents and occupational diseases to chronic sickness and disability, in Belgium about 22% of invalidities and disabilities are the result of work accidents and occupational diseases (ISP, 2002). But 32% of men with an invalidity or a disability

declare work accidents and occupational diseases as the cause of their ill health. For people aged 45-54 the situation is even worse. About 38% of those with an invalidity or a disability declare work accidents (28.4%) and occupational diseases (9.4%) as the cause.

Flexibility has been held up as a significant factor in physical accidents and higher rates of mental ill health. P. Askenazy (2001) found an apparent correlation between the adoption of high-performance practices and a dramatic increase in occupational injuries and illnesses in the USA. Total quality management, job rotation and autonomous work teams are believed to be harmful to workplace health and safety. They increase the intensity of work both in manufacturing and tertiary industries. Increased intensity of work has also been found in European countries (European Foundation for the Improvement of Living and Working Conditions, 1999a).

Numerous Scandinavian studies report that quality and participatory practices improve safety and health, while in France some studies show that the adoption of new workplace practices is associated with higher pressure on workers (P. Askenazy, 2001).

Strains at work can be divided into<sup>4</sup>:

- environmental stress (e.g. noise, steam, heat);
- physical stress (e.g. lifting heavy loads, uneven muscular strain); and
- psychological stress (e.g. monotony, time pressure, management behaviour)<sup>5</sup>.

The German Federal Statistical Office found that in recent decades a structural change in the nature of stress, from physical to psychological, could be detected. But between 1985 and 1991, in addition to the increase in psychological stress, there was once again an increase in physical stress.

In Spain a rise in work injuries, by 9.4% between 1996 and 1997, has coincided with increased employment flexibility (C. Amuedo-Dorantes, 2002). There has also been a rapid growth in work-related illnesses. A survey conducted by the Spanish Department of Labour suggests that the most important determinant of the likelihood of work-related injury and illness is working conditions, rather than education or job tenure.

This runs contrary to the established view that temporary workers have in general a higher incidence of work injury and illness. Proposed explanatory factors for this view often include:

- lack of training and experience, and
- greater pressure as they have to meet demands for increased production in a short time.

C. Amuedo-Dorantes noted that the percentage of temporary workers employed in particularly poor conditions was higher than that of permanent workers in Spain. But, with working conditions constant, there was no statistically significant difference in work accident rates for temporary and permanent employees. She found that the probability of temporary employment was higher in

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<sup>4</sup> Federal Statistical Office (Germany), 1998.

<sup>5</sup> In 1993, approximately 282,000 cases of inability to work resulting in about 10.9 million days off work (2.2% of all days off) were attributed to depressive illness in Germany (Federal Statistical Office, 1998).



establishments offering poor working conditions. So temporary work contracts were likely to be characterised by worse conditions than permanent work contracts. She concluded that, once the data have been controlled for workers' type of contract, working conditions rather than workers' educational attainment or job tenure appear to affect employees' likelihood of work injury.

The Foundation (1999a) reports similar results, noting that the working conditions of temporary employees are worse than those of permanent workers. The former are more exposed to discomfort, intense noise, repetitive movements and short, repetitive tasks. However, this study suggests that different types of employment status have an independent effect on the health-related outcomes studied, regardless of working conditions. From all this it may be concluded that both working conditions and employment status have independent effects on health-related outcomes.

In general, companies do not themselves pay for the social consequences of bad working conditions. In many countries the disability premiums or contributions paid by individual employers in a given industrial sector do not depend on the number of work accidents in their own companies. Only recently have some countries imposed financial costs on companies with a high rate of accidents. In France the employer has to pay a fine to the government in cases of work accidents or occupational illness. In the Netherlands the employer has a financial responsibility for both the first year of sick leave and five years of follow-up benefits. Since 1998 the Netherlands has imposed a differentiated insurance premium: the amount of the premium depends on the benefits paid to disabled workers from the firm.

Critics argue that this differentiated premium may push employers to reduce their hiring of vulnerable groups that might present higher risks for the employer. In order to avoid this adverse selection the Dutch government gives a special budget to employers who hire employees with weak health (P. Besseling et al, 1998).

In its Resolution of 3 June 2002 on a new Community strategy on health and safety at work (2002-2006), the Council notes that in order to achieve the aim of constantly improving well-being at work, the parties involved must pursue a number of objectives, including:

- Reducing the number of occupational accidents and illnesses. Quantified objectives should be set; this presupposes stepping up the work in progress on harmonising statistics on accidents at work and occupational illnesses.
- Placing more emphasis on the prevention of occupational illnesses, especially those that continue to affect a large number of European workers; for example, ones caused by the use of dangerous substances such as asbestos, hearing loss and musculo-skeletal disorders.
- Taking into account social risks such as stress and harassment at work, as well as those associated with dependence on alcohol, drugs and medicines.
- Taking into consideration changes in the composition of the labour force due to greater numbers of women entering the labour market, the ageing of the workforce, demographic change, the circumstances of workers with disabilities, and ethnic and cultural diversity in the workplace, as well as the resulting implications in assessing and preventing risks of accidents.

Exceptions to definitions of occupational diseases have always been made for mental problems such as stress, depression and job dissatisfaction. It is difficult to prove these cases, especially the

link with working conditions. Women often report such problems as they consider that existing criteria are designed to fit industrial workers but are not relevant to the tertiary sector (office work, etc.). Consequently, many women working in the services feel discriminated against.

Segmentation of the labour market has led women and men to work in gender-segregated occupations, with very different occupational health risks. The well known over-representation of women in certain jobs, such as care and nursing services, presents its own occupational health hazards, which do not generally fit into the traditional lists of occupational diseases.

## **Mental health disorders<sup>6</sup> and living conditions**

The World Health Organisation (WHO) distinguishes physical health, mental health and social health. The present section focuses on mental health but does not cover mental handicap (learning disabilities). However, behavioural disabilities and handicaps in human relationships are used as indicators for mental conditions in certain classifications. Consequently the terms mental health and social health are used synonymously in some studies. Here social health refers to the quality of the interaction between individuals and their social environment.

Health surveys in general include three dimensions:

- anxiety and insomnia,
- social dysfunction, and
- depressive moods.

A person has a psychiatric morbidity if he receives a score over a certain cut-off point. However, it is generally accepted that mental disorder is more difficult to assess than, for example, physical impairment.

The WHO estimates that in Europe at least 5% of the population suffer from serious diagnosable mental health disorders (neuroses, functional psychoses, mental retardation). It is further estimated that at least an additional 15% suffer from less severe but potentially incapacitating forms of mental distress (A. de Bruin et al, 1992). This last estimate is quite high but it does include minor and short-lived disorders. By comparison, according to the Danish Psychiatric Association, 20% of the adult Danish population will have had a non-psychotic mental disorder (anxiety, depression, alcohol abuse), during 2002 (C. Csillag, 2002). But this figure derives from consultations and a consultation is not equivalent to an impairment or disability. About 25% of new disability benefits in Europe are due to mental conditions, and this share is increasing. In Austria emotional (psychological) disabilities were the most frequent reasons for entitlement to disability pensions and represented 31% of new cases in 2000 (Brunel University, National Reports, 2002). In the Netherlands about 35% of the total number of disability benefit recipients in 2001 were unfit to work due to mental disorders (European Foundation for the Improvement of Living and Working Conditions, EIROOnline).

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<sup>6</sup> This part draws on studies done by the World Health Organisation (WHO).

It is estimated that mental disorders will account for 22% of the total burden of disease in 2020. Furthermore, depression could become the second most important contributor to the global burden of disease by the year 2020 (H. Whiteford et al, 2001). Alcohol and drug dependence also account for significant shares.

Certain groups face a higher risk. Belgian data indicate that these are (F. Kittel, 2001):

- divorced women,
- disadvantaged social classes.

The Belgian Health Interview Survey (ISP, 2002) reported that about 5% of men, but 8% of women, experienced depression during 2001. More generally about 10% of men, but 16% of women, experienced mental health problems. As a result 10% of men and 17% of women took psychotropic medicines (tranquillisers, sleeping pills, antidepressants). Similarly in Germany around 6% of the population suffer from depression (Federal Statistical Office, 1998), but the proportion of women is more than twice as high as men. Similar results are found in Sweden (Socialstyrelsen, 1998).

It is also interesting to note that, unlike physical disabilities, the prevalence of psychological problems does not increase with age (S. Grammenos, 1995, ISP, 2002). The prevalence rate seems stable across ages, unlike limitations affecting mobility, the senses and the ability to care for oneself, which are strongly related to age. Only senile dementia, often coupled with depressive moods, increases significantly with age.

Furthermore, according to the Belgian survey, mental health problems are associated with:

- physical co-morbidity (diseases or disability),
- risky behaviour,
- poor (less good) social health.

Elderly people also appear to be a risk group, notably due to:

- life events (retirement, death of partner),
- a forced move to an institution (due to a lack of care services at home),
- reduction in social contacts.

M. Lindeboom et al (2001) analysed the health of elderly Dutch people by using longitudinal data. They confirm the general belief that institutionalisation has negative effects on both emotional and cognitive abilities. Life events like conjugal bereavement, the death of grandchildren and illness of a partner or close relative, are crucial triggers of chronic depression. The authors therefore conclude that governments should consider the above as a high-risk group. This could avoid the future need for costly formal long-term care services.

Information campaigns have tried to de-stigmatise mental illness, but there is still a strong stigma attached to it. In many European countries priority is given to treatment within the community, but large hospitals still remain in the former eastern bloc.

The WHO believes that drug abuse in Europe is increasing. It reports that in Western European countries the use of cannabis is widespread among young people and the consumption of amphetamine-type stimulants and cocaine continues to increase (WHO, EHR, 2001). However, data on the prevalence of drug use in Europe are scarce. In Belgium it is estimated that the number of injecting drug users amounts to 0.36% of the 15-54 age group (F. Sator et al, 2001).

Initially policies were designed to eradicate drug dependency altogether. Later they aimed at 'stabilising' addicts by using substitutes (methadone) and helping them to live independently. Current research on heroin addicts (the Netherlands, Germany, Switzerland) proposes that they should be registered and provided with drugs on prescription (Van Kolfshoeten, 2002).

The European Commission, in its report on social inclusion (2001), notes that mentally ill people and drug and alcohol abusers experience particular integration problems and face an especially high risk of persistent poverty. Along with the homeless, ex-prisoners and prostitutes, they make up the group with the highest risk of persistent poverty.



## The civil rights approach

Attitudes to people with disabilities are changing significantly. From seeing people with disabilities as the passive recipients of charity, society has come to recognise the legitimate demands of disabled people for equal rights. Traditional economic and social processes have tended to be built on assumptions about normality that have not taken into account people with disabilities. As a result, activities that the rest of society takes for granted have often been denied to people with disabilities. Barriers have prevented their full participation in society.

Previous definitions have implied that the interviewees themselves are the 'problem'. The starting point in the surveys has been 'a chronic physical or mental health problem, illness etc.'. In the administrative definitions stress is put on 'work reduction capacity' and 'limitations' in activities of daily living. The approaches adopted seem to accept a causality in the following direction:

*P. Wood (ICIDH)*

Impairment ——— > Disability ——— > Handicap

*S. Nagi (Disability in America)*

Active pathology ——— > Impairment ——— > Functional limitation ——— > Disability

The medical approach assumes that the 'problem' of disability arises solely from physical or mental impairments. The person with a disability is seen as having an individual problem for which some form of treatment or rehabilitation is necessary. A causal relationship runs from impairment to social disadvantage.

The civil rights approach considers that disability is a restriction of activity caused by a contemporary social system that takes little or no account of people who have physical impairments and thus excludes them from the mainstream of social activities (J. Pitcher et al, 1996).

The disability movement questioned the traditional assumptions and highlighted the interaction between an individual's impairment and his social and physical surroundings. By doing so it has demonstrated how society has imposed physical and attitudinal barriers preventing the full participation in everyday life of people with disabilities (R. Whittle, 2000). The disability is seen as a social construct. The social model stresses the discriminatory barriers in society and argues that society must be modified in order to include and accommodate the needs of everybody, including people with disabilities.

Furthermore, the social theory of disability maintains that disability is an outcome of social attitudes and social structures. People with disabilities make up a minority group that experiences discrimination, as do other minority groups, at the hands of a dominant group (white, able-bodied males) (Harlan et al, 1998). Unfair treatment may arise from 'patterns of dominance and oppression, viewed as expressions of a struggle for power and privilege' (G. Marshall, 1994).

Taking into account the social theory of disability, the British Council of Disabled People believes that disability is the outcome of the interaction between the person (with the impairment or health

condition) and environmental factors. It specifies that environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. According to this view, the right question to ask people with impairments or health conditions is: 'Are there problems caused by the physical environment, the work environment or the attitudes of others?' Answers to such a question may clarify what adjustments society has to make.

In summary, society pushes people with illness and disability into a situation (of social exclusion) that lies beyond their control. These critiques led to a revision of policies in favour of people with disabilities and the acceptance by policy-makers of the importance of environmental and attitudinal factors.

### Characteristics of social exclusion

According to the European Commission (COM(2000)), social exclusion is a multidimensional phenomenon. It is linked to activity status as well as to a number of indicators that relate to an individual's means, perception and satisfaction, all of which are key determinants of people's standard of living and quality of life. The challenge is not only to provide better help to those excluded (or at risk of exclusion), but also to address actively the structural barriers to social inclusion in order to reduce it. Furthermore, the Commission holds that employment is the key route to integration and social inclusion: unemployment is the major factor in exclusion. However, social exclusion goes beyond issues of unemployment and access to the labour market. It calls for attention to education, training, access to public and private services and emerging new forms of work.

Social exclusion is characterised by five key factors (G. Room, cited in Tsakloglou et al, 2001):

- it is multidimensional: it includes not only income but a wide range of indicators of living standards;
- it is dynamic: specific factors determine entry or exit from it;
- it has a neighbourhood dimension: deprivation is caused not only by lack of personal resources but also by unsatisfactory community resources;
- it is relational: it implies inadequate social participation and lack of power;
- it implies a major discontinuity in the relationship of the individual with the rest of the society.

Exclusion includes processes by which social groups or individuals are excluded from full participation in any aspect or activity (social, economic, political, economic, cultural, etc.). In general it includes:

- a) legal exclusion (for example, denying access to certain jobs to people with disabilities);
- b) economic exclusion (due to economic deprivation);
- c) physical exclusion (due to physical barriers);
- d) exclusion due to lack of provision (for example, absence of relevant translation for deaf people);
- e) exclusion due to stigmatisation (for example, de facto discrimination against people with HIV/AIDS) (N. Krieger, 2001).

The European Commission in its report on social inclusion identifies ten risk factors (European Commission, 2001):

1. Long-term dependence on low or inadequate income
2. Long-term unemployment
3. Low quality employment or absence of employment record
4. Low level of education and illiteracy
5. Growing up in a vulnerable family
6. Disability
7. Health
8. Living in an area of multiple disadvantage
9. Precarious housing conditions and homelessness
10. Immigration, ethnicity, racism and discrimination.

For people with disabilities there is a cumulative disadvantage. In fact, they share most of the criteria above, e.g. low income, unemployment, low level of education, poor health, etc.

According to a European study by the Greek National Confederation of Disabled People and the European Disability Forum (2002), participants in their survey believe the following factors either important or very important:

1. Lack or limited access to social environment, as well as unemployment
2. Lack or limited access to services
3. Stigmatisation of disabled people
4. Lack of adequate training
5. Lack of specialised services
6. Lack of economic policies to compensate for the extra costs of disability
7. The structure of the benefit system
8. Living in institutions.

The areas of intervention might be different, but there are many factors that are common. Inclusion policies require the ability of people to participate fully in the political, economic, social and cultural functioning of the society in which they live. It implies equal opportunities, empowerment and active citizenship in mainstream society.

## **Poverty and stigmatisation**

The European Commission (2001), in its report on social inclusion, notes that the actual living standards of those living below the relative poverty line are strongly conditioned by a number of factors. These include house ownership, health conditions, security of work income and the need for extra care for elderly or disabled members of the household. Illness and disability appear as major determinants of poverty and exclusion.

Member States have developed a wide range of instruments to help those in need. Critics of social protection argue that they provide benefits to people who could otherwise work. But many studies report that some people who satisfy the conditions for disability and other social benefits do not



apply for them. Lack of information or other sources of income (for example, different social benefits or their own financial resources) are often put forward as possible explanations.

The following table shows that a high proportion of people with disabilities receive no income. They represent 1.36% of the total working-age population. The OECD (2002) reports a slightly higher percentage but for a different age group.

**Table 6 Persons with a chronic illness or disability without income**

		%		
		Persons with a disability		
		Severe	Moderate	Total
1	Population with illness/disability EU (14) Age: 16-64	4.5	10	14.5
2	% of (1) without income	8	10	9
3	without income as % of pop. 16-64	0.36	1.0	<b>1.36</b>
<hr/>				
4	Population with illness/disability EU (11) Age: 20-64			15.6
5	Non-employed with illness/disability			59.2
6	% of (5) without income from work or benefits			24.7
7	without income as % of pop. 20-64			<b>2.28</b>

Source: Eurostat, 2001 and OECD, 2002.

However, these percentages may overstate the number of disabled people without income, as some beneficiaries might not declare benefits. It is a well known problem that most surveys undercount the number of beneficiaries of most benefits.

By comparison, in Germany, where the estimation is more elaborate, about 63% of all poor households do not take up the income support available to them (Riphahn, 2001). This represents 2% of all German households.

In France about 6% of the population asked for help or recognition of their disability, but only about 5% were accepted (see Figure 4). This represents 1% of the total population, but an important share of people with disabilities: 20% of those recognised. However, the existence of alternative sources of income means that some may receive another form of benefit, provided they are willing to apply for it.

Figures 12 and 13 indicate that there are huge variations across countries. Objective 1 countries (Italy, Spain, Portugal) have a high percentage of disabled people without income from work or benefits. The OECD (2002) notes that this might be the result of a dual benefit system in these countries (contributory and non-contributory). Non-contributory benefits are means-tested and often impose stringent conditions.

Furthermore, social assistance benefits require a much higher degree of disability in these countries, compared with social security schemes. Therefore many people reporting a disability degree of less than 50% could be excluded from disability benefits.

**Figure 12 Share of non-employed disabled persons without income (from work or benefits), by age group**

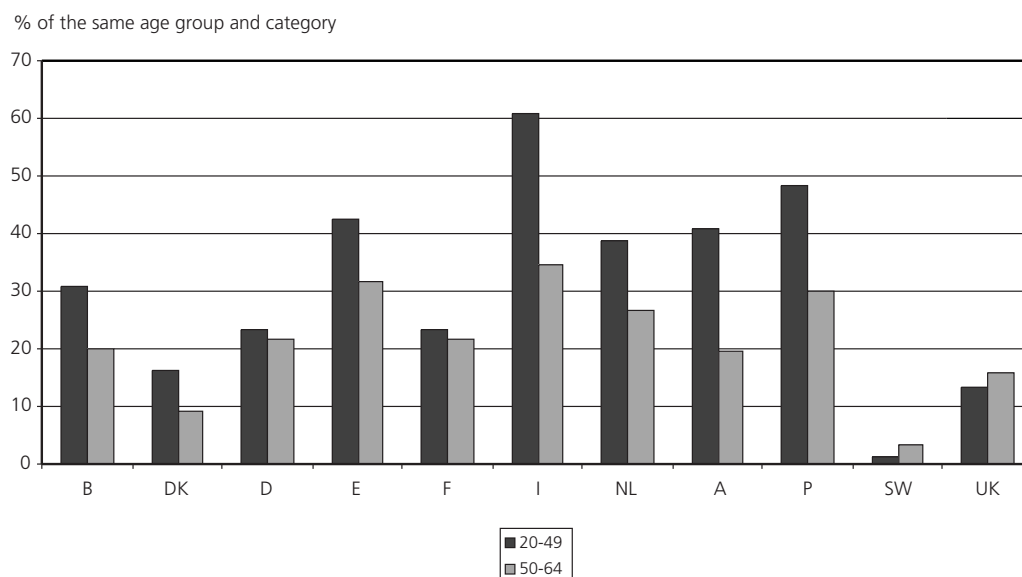
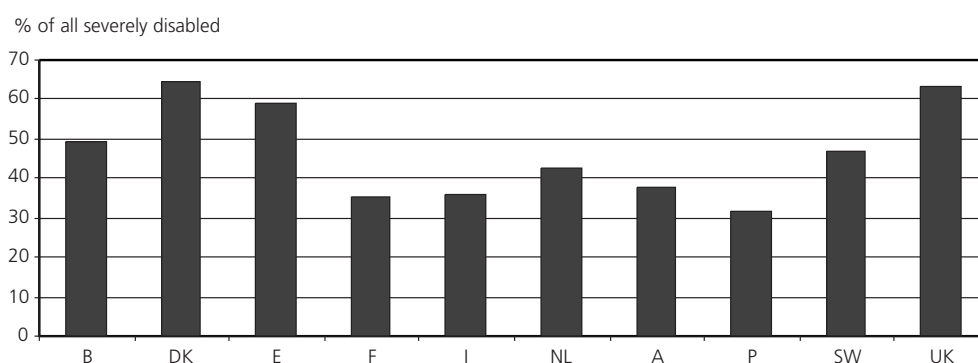


Figure 12 also shows that there is a significant difference between younger groups (20-49) and older ones (50-64). The percentage of disabled young people without income (from work or benefits) is higher compared with older people in all countries, except Sweden where both are extremely low.

This could be the result of the following factors:

- older workers more easily satisfy conditions such as a minimum number of days at work, etc.;
- stigmatisation.

**Figure 13 Severely disabled: disability benefit reciprocity rates**



Source: OECD, 2002. Survey data.

Younger people might feel more strongly the adverse impact of being labelled 'disabled' or 'sick'. In fact, someone wanting to take part in a programme will take into account the expected benefits and the possible stigma attached to it. They will take part if they feel the net benefit (taking any stigma into account) outweighs the alternatives. Participation in a disability scheme might generate

a high cost in terms of employment, social relations, etc. This could, for example, be an adverse signal to prospective employers, reducing the chances of future employment. So the non-take up of available assistance could be a rational choice.

According to a recent survey covering the Member States (Greek National Confederation of Disabled People, 2002), organisations representing people with disabilities and the main actors in the field holds that around 94% of disabled people receive inadequate disability benefits to cover their needs. The study concludes that a large proportion of people with disabilities are in the lowest part (bottom tenth) of the spectrum of income distribution.

# Barriers to participation and independent living

## Autonomy

Autonomy is the ability to make decisions for oneself and to carry them out. A constraint or a dependency may arise and restrict the extent of one's choices. In some cases constraints can be nullified by society, in other cases the dependent person needs help from others to maintain a normal life. These factors empower disabled people to control their own lives as far as possible and to have the freedom to participate fully in the life of the community. Support in these cases includes personal assistance, information, housing, education, access to the environment and to the political arena.

Autonomy and independent living mean that people with disabilities have the same choices and control in their everyday lives that non-disabled people take for granted: growing up within their families, going to an ordinary school, using the same bus as other people, starting a family and so on – just like everybody else (A. Ratzka, 2002).

Everyone has the right to be able to live on equal terms with others, and to have the chance to lead as normal a life as possible. For example, children with disabilities have the right to live with their parents as others do. People with disabilities have the right to a good child care service and education, the opportunity to work and to have a family, good housing and a chance to take part in different cultural and leisure activities.

The problem with the provision of services is that people with disabilities are still far too often seen solely as objects of care. As a result disability policy is regarded as a matter of providing care and not as a matter of democracy and equal rights. Various services are offered in the Member States, but often in a fragmented way without any consideration as to whether they will promote real independence.

Also, people with severe chronic illnesses or disabilities are largely cared for in the family. They become particularly vulnerable when caring parents become old and frail. Institutions remain the main alternative service providers, but their social life and levels of care are often inadequate and may further aggravate marginalisation and exclusion.

The Nordic countries, whose previous policies assumed that a place in an institution was a right, have reversed their approach. Current emphasis is on dismantling institutions and supporting people in the community. However, an inadequate or expensive care system leads in many cases to the family shouldering the full burden of support.

Costly or inadequate provision of services has led many families to care for their children, spouse or parent at home. Most of these carers are women (mothers, wives or daughters) and in some cases they have to work part-time or give up their work. This creates financial problems, and puts them at a disadvantage and at risk of poverty and marginalisation.

Applying a disability perspective to our thinking means starting from the view that different people have different needs. Disability is just one of the variations in our population. The same rights can be met in different ways according to differing needs.

### **Different types of barriers**

European citizens tend to be severe in their judgement of the level of access to equipment and events for people with disabilities. Overall, they see this access as 'fairly difficult' to 'very difficult' (European Commission - Eurobarometer, 2001). About 97% of Europeans think that something should be done to involve people with disabilities more in society. Despite this general consensus, public policy is lagging behind and barriers are still in place.

Access to society is a fundamental right, and a critical goal for the disability movement. Most people think of access barriers purely in terms of the wheelchair user who is denied entry to a building by a flight of steps. In fact 'access' is much wider. It relates to physical environment, information, services, economic activity, culture, language... the list is endless. A fundamental debate on universal access from a conceptual, political and practical perspective is necessary.

The debate ought to agree on the principle of the equal worth of all human beings as fundamental to the design of our societies. Society ought to be designed in such a way as to allow everyone to contribute to its development and to enjoy full participation in the life of the community. Currently, obstacles prevent the disabled from exercising their right to participate fully in society.

All surveys present limitations in mobility as the main source of disability. Mobility plays a crucial role in ensuring participation in economic and social activity, and the lack of it is a factor inhibiting the right of people with disabilities to participate. Enabling people with disabilities to take part fully in the life of a society requires the removal of all kinds of barriers that exist in public infrastructures, transport, communications, information, culture, religion, language and so forth. The approach to disability endorsed by the Council (Council, 1997) is that barriers are an important impediment to participation in society, and that accessibility and mobility issues ought to be seen in the light of equal opportunities and the right to participate.

### **Physical barriers**

If people with disabilities are to access education, employment, leisure and other activities, it is vital that they can reach them. This means that they must have access particularly to buildings and transport services.

Premises that are open to the public, such as shops, restaurants, cinemas, post offices, schools and courts of law, are often inaccessible to people with disabilities. The same observation also applies to public places such as streets, squares and parks. These and other premises may be privately owned or the property of the municipality or the state. A study in Sweden, where the situation is better than in other countries, has shown that less than half the entrances to public premises are equipped with ramps. The corresponding figure for commercial premises is 20-30% (Ministry of Health and Social Affairs, Sweden, 2001). The same report notes that even new buildings often have shortcomings, for instance in the location of door openers and the design of lavatories. Colour schemes may also be poorly chosen and lighting is often inadequate. It seems that accessibility in newly built dwellings has deteriorated in the '90s.

A French study of 61 universities reveals that 50% are not accessible to people with disabilities (A. Danel, 2002). There are access barriers to classrooms, secretariats, libraries, sanitary facilities and

so on. In Sweden, the Office of the Disability Ombudsman found that at one school in four it was impossible for people in wheelchairs to reach the main entrance. In one out of three schools, narrow doors or high thresholds constituted obstacles for people with disabilities (Ministry of Health and Social Affairs, Sweden, 2001).

At present the disability perspective is rarely integrated into planning. Instead of making an environment accessible from the very outset, far too often special solutions are found at a later point that prove to be more costly and more unwieldy than would have been the case if the disability perspective had been included from the beginning (Ministry of Health and Social Affairs, Sweden, 2001).

It appears that the greatest number of obstacles is found in the outdoor environment. These include kerbs, steps, steep slopes, changes of level, the choice of paving, and features that make it difficult for people with impaired orientation capacities to find their way (Ministry of Health and Social Affairs, Sweden, 2000). Extra distances, for instance to get round the obstacles, add still further to the physical effort required. An interesting initiative in Sweden asks the National Board of Housing, Building and Planning to clarify existing requirements for accessibility in the Planning and Building Act. The Board ought to give priority to issues of accessibility for the elderly and disabled. Local disabled people's organisations are invited to participate.

As a setter of norms for builder, purchaser, manager and tenant, the state has a responsibility to demand that people with disabilities are able to take part in the same activities as everyone else and as far as possible to make use of the same goods and services (Ministry of Health and Social Affairs, Sweden, 2001).

The discussion on accessibility often takes into account only the cost of adaptations and neglects the fact that these reduce the need for help and make it easier for people to manage their own lives. This in turn reduces the services that have to be provided and so brings long-term benefits to society.

The European Disability Forum believes that the 'Design for all' approach presents the following advantages:

- Appropriate design in technology reduces the need for human support and empowers disabled people because it reduces dependence on others.
- Technology may support disabled people's ability to achieve independent living.
- Incorporating disability standards at the design stage is also a cheaper solution than adapting products and standards or making special provisions. Such adaptations are expensive, time consuming and ultimately discriminatory.
- The vast opportunities offered by the information society will change the lives of nearly all disabled people.

### **Legal and administrative barriers**

Some legal barriers reduce the choice and autonomy of people with disabilities. They often deny employment access for people with disabilities to sectors like the armed forces and the police. In many countries services such as these are exempted from anti-discrimination laws.

In addition, people with intellectual retardation or with psychological problems are refused the right to manage their own lives. Initiatives in this direction are rare, but one such initiative – to remove legal barriers and enable disabled people to increase their possibilities – has been taken by Denmark, where people with a psychological deficiency may manage their goods.

In Sweden, two-thirds of the government authorities had no information in Braille, on cassette or in easy-to-read form. Four out of ten authorities were not even prepared to make information available in suitable forms on request (Ministry of Health and Social Affairs, Sweden, 2001). A 1999 survey revealed that over half the county administrative courts were not adapted to the needs of people with mobility problems and lacked facilities to adapt them to the needs of people with impaired hearing.

### **New technologies**

Developments in technology, particularly information technology, can offer tremendous opportunities but could also build new barriers for disabled people, if their needs are not taken into account at an early stage. New technologies play an increasing role both at home and at work. Their use can offer new opportunities in many areas and can expand choice. Conversely barriers to their use by the disabled may significantly reduce choice and exclude them from social, economic and cultural activities.

The rapid growth of information and communication technologies presents new opportunities for products, services and jobs for many people. They can be used to improve the quality of public services, and to make jobs more accessible and participation easier for some people with disabilities. But for some these new technologies may become a new barrier and may consequently widen the gap that already exists.

People with disabilities face a wide range of barriers in accessing the Internet. The European Commission (2001) believes that, as government services and important public information are becoming increasingly available online, ensuring access to public websites for all citizens is as important as ensuring access to public buildings.

The principle of functionality and accessibility ought to permeate all public construction projects. An effort should be made to determine a minimum set of guidelines to be applied to private projects open to the general public. The disability perspective should be taken into account whenever public financial support is involved.

On 12 May 2000, the Commission formally adopted a Communication on a 'Barrier Free Europe for People with Disabilities' (European Commission, 2000). This focuses on how policies can give disabled people the right to mobility in areas such as the information society, the opening of the internal market for technical aids and the protection of disabled consumers' rights.

Barriers faced by disabled users of the web include:

- for people with visual disabilities: graphics are unlabeled; the tables/frames are poorly marked; there is a lack of keyboard support or screen reader compatibility;

- for people with hearing disabilities: there is a lack of captioning for audio, or a proliferation of text without visual signposts;
- for people with psychological disabilities: there is a lack of keyboard or single-switch support for menu commands;
- for people with cognitive or neurological disabilities: there is no consistent navigation structure; or there is overly complex presentation of language; or lack of illustrative non-text material; or flickering designs on pages.

### **Mental barriers – attitudes**

Legislation is not enough to change attitudes towards people with disabilities. Complementary measures are needed in order to achieve rapid change. Along with physical barriers, negative attitudes towards disability must be challenged for equality of opportunity for people with disabilities to be successfully attained.

A sustained communication programme is often needed to challenge negative attitudes towards, and ignorance of, people with disabilities and to ensure that everyone understands the contribution they can make. It is important, in this respect, to define strategies that can present people with disabilities as people with equal rights and not only as needing help. Everyone should understand why an equal opportunities policy is required and what it means.

In the labour market, employers often have a tendency to look more at the disability than at the actual ability of the person in question. Consequently, their value to a company can be underrated. Some Member States have run systematic information and sensitisation campaigns by agencies coordinating or monitoring policies in favour of people with disabilities. These agencies may also ensure continuity in the different campaigns over a period of time (e.g. Denmark, Ireland, the United Kingdom).

### **Segregation**

#### **Education**

'Mainstreaming' can embrace all human activities, but especially education, training and employment. Segregation begins at an early stage by pushing disabled children into parallel networks of education. This segregation in its turn creates stereotypes, misconceptions and mutual ignorance. A dynamic exclusion process begins that further strengthens misunderstanding, wrong attitudes and discrimination.

Including disabled children in mainstream education throughout their school lives is one of the most powerful ways of banishing stereotypes and negative attitudes towards disabled people in the next generation. The education of disabled children side by side with their non-disabled peers avoids social marginalisation, strengthens social ties, provides a wider array of educational choices and consequently determines future opportunities in life. It is clear, therefore, that mainstreaming ought to begin at school.



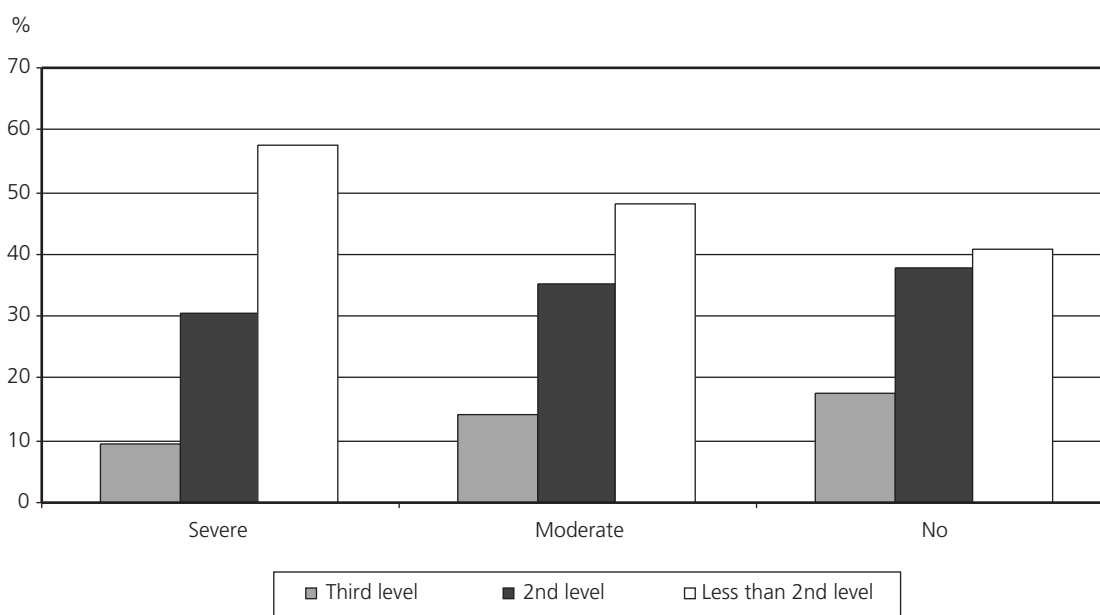
Nevertheless, a right that society takes for granted is often refused to disabled children or provided with conditions that hinder them from exercising that right. Many children are still excluded from mainstream schools simply on the grounds of restricted mobility, sensory impairment or communication difficulties. All too often children with disabilities are confined during their school years (and even beyond) to institutions which, while providing special care, nonetheless isolate them and give them drastically reduced opportunities, or none at all, for mainstream social engagement.

Specialised networks aim to cater for disabled people who cannot take part in ordinary education programmes. However, they often cater for pupils who could otherwise join the ordinary education system if the necessary help was provided and reasonable adjustments made. According to a European study (Greek National Confederation of Disabled People, 2002), only around 59% of children with special needs are in mainstream schools, despite the fact that the remainder could participate in mainstream education if they received the necessary support.

Analysis of national situations indicates that at an early stage pupils with special needs do try to integrate into ordinary schools. But the lack of adequate human and technical support leads them into special education. In fact there is a relatively high concentration of children aged 10-13 in special education. After this age there is a relative decline of disabled pupils in all types of schools and an early exit from the educational system (S. Grammenos, 1995).

People with disabilities have lower educational attainment, which in turn affects their future employability. The following graph shows that they have less chance to reach the highest level of education and greater likelihood of ending their studies prematurely.

**Figure 14** Distribution of the population by disability status and level of education



Source: Eurostat, 2001.

The number of children with special needs varies sharply between countries, depending on the chosen definition: from 1.2% in Italy to 17% in Finland (M. Fardeau, 2001). The inclusion of children with learning difficulties may raise the numbers very considerably. A large number of children with special needs are integrated into ordinary schools, notably, in Denmark, Italy, Finland, Sweden and recently the United Kingdom. But in some countries this tendency has weakened. In the remaining countries segregated structures are used extensively.

In Germany, about 5% of pupils have a recognised disability. The vast majority are in special education (4%) and only a minority are in ordinary classes (1%) (OECD, 1999). In the United Kingdom, of the 2.9% of children recognised as having special needs, about 1.3% are in special schools and 1.6% in ordinary classes.

On the relationship between the type of disability and special education, it is worth noting that in certain countries there is a policy of guiding children with learning difficulties towards special education (e.g. Germany, Greece, the Netherlands). Available statistics show that girls are generally under-represented in both ordinary and special schools (S. Grammenos, 1995). In some Member States most children with specific needs do not go beyond primary education, mainly due to the absence of adequate support and infrastructure (notably in Spain, Greece, Ireland and Portugal).

New approaches stress needs and context rather than disability. With this in mind, schools should take down barriers and provide all necessary facilities to pupils with special needs. The guiding principle is of a global school open to everybody. Special education could be limited to children who would not benefit from attending ordinary schools. In certain countries there is an increase in special classes within ordinary schools at the expense of integrating pupils individually. While this could be desirable for severely disabled children, who could not otherwise attend ordinary schools, there is a risk that small, special units will develop on the premises of ordinary schools without any link or exchange with mainstream classes.

In some countries the medical approach prevails. This stresses impairments (Belgium, Germany, Austria, Netherlands, France, etc.), and education is organised around a huge variety of specialised institutions where medical criteria dominate.

Integration into ordinary education, training and employment schemes, alongside their non-disabled peers, enables disabled people to take full advantage of the diversity that the open system offers. Also, people with disabilities who are integrated into ordinary structures are more likely to develop the social and vocational skills – and the social networks – that will enable them to adjust to the community and to the demands of the open labour market.

### **Vocational training**

The European Commission (2001), in its report on social inclusion, notes that a disproportionate number of people with disabilities are considered ineligible for training because their educational levels are too low. They propose applying less restrictive eligibility criteria and make training and the updating of skills more accessible. Special measures have been taken towards achieving this in Sweden, Finland and Austria.

As noted above, discrimination pushes people with disabilities towards investing less in human capital. This means that measures are needed to keep the young disabled in ordinary schools and to improve the quality of special education.

One important question relates to the image special education and training have among the general public, and employers in particular. For children with disabilities, special school could be associated with a refusal to accommodate their needs in ordinary schools. For an employer special education does not convey the same information as ordinary education. Lack of information could make the employer consider a disabled candidate for a vacancy as more risky. Furthermore, the employer cannot tell whether someone with a disability had to go to a special school because of innate problems or the lack of technical aids. Finally the different curricula followed by special schools could further increase confusion about the nature and quality of the training provided. In this respect, it is questionable whether impairments need to be highlighted in the curricula followed by special schools.

The European Commission in its report on social inclusion identifies ten risk factors (European Commission, 2001). The first three of them relate to the labour market (long-term dependency on low or inadequate income, long-term unemployment and low quality employment or absence of an employment record), with disability and health as independent factors.

It appears that the labour market plays an important role in the process of exclusion and marginalisation. So the sections following look at specific problems faced by people with chronic illness and/or disability in the labour market.

## **Participation in the labour market of people with illness or disability**

The following figure indicates that non-participation in the labour market of people with disabilities is almost twice as high as it is for non-disabled people. About half the severely disabled aged 30-50 are not in the labour market while the rate for the moderately disabled is about 30%. The difference here between the moderately disabled and non-disabled is relatively small. On the other hand, the difference between the severely disabled and non-disabled is high. One may wonder whether this difference could be reduced significantly.

The figure indicates that active policies could focus on the 50-65 age group. In fact non-participation increases drastically for everybody after the age of 50. This is true both for disabled and non-disabled people and could be the result of early retirement schemes. Furthermore, the figure shows that non-disabled people leave the labour market faster than disabled people. The lower participation rate of young people could be the result of them being in higher education and vocational training. So this could not be considered as real inactivity.

The ageing of the population is expected to increase the number of dependent people relative to the number of the working-age population (the dependency ratio). This will probably put pressure on the financing of pension schemes and so raises questions about the long-term viability of existing social security schemes. Current policies aim to compensate for the increase in the dependency ratio mainly by the increase in labour participation and the rise of the retirement age.

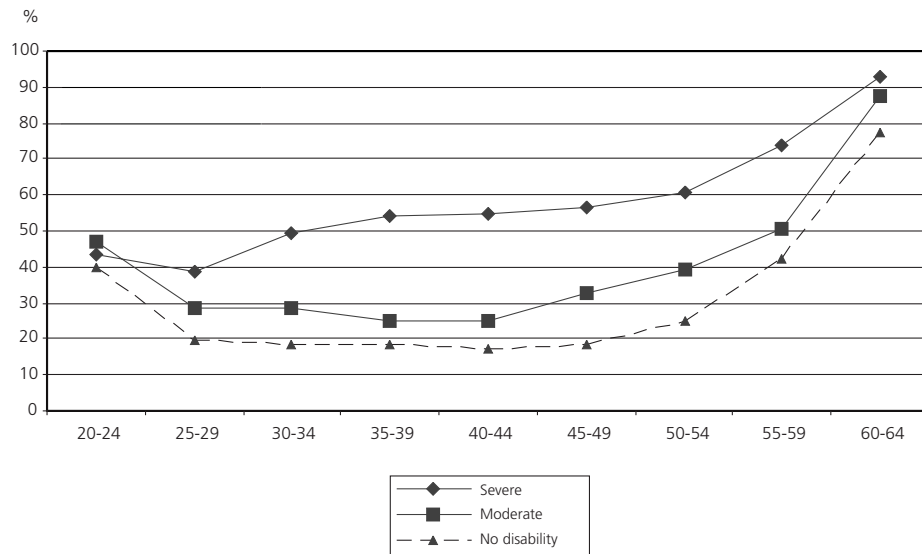
The figure indicates that policies ought to focus on all groups (disabled and non-disabled) and target older workers. This policy, however, has to take into account the evolution of health. People with reported poor health have very different participation rates. Bound finds that it is not poor health at an older age but deteriorating health, which helps to explain retirement (J. Bound, 1998). This means that a policy aiming to increase the participation in the labour market of people with deteriorating health could turn moderate disabilities into severe disabilities for older people.

The British data indicate that the proportion of those with support needs is higher among those who are inactive (20%) than among those who are active in the labour market (8%) (N. Meager et al, 1999). This could be interpreted in two ways. Firstly, it is likely to reflect the fact that the inactive group includes a higher proportion of people with severe disabilities. Secondly, the needs are likely to be greater than suggested simply by looking at disabled people already at work. Inactive people do not participate in the labour market, not because their disability is more severe, but because they are not offered the necessary work adaptation or technical aids. In fact, many inactive people

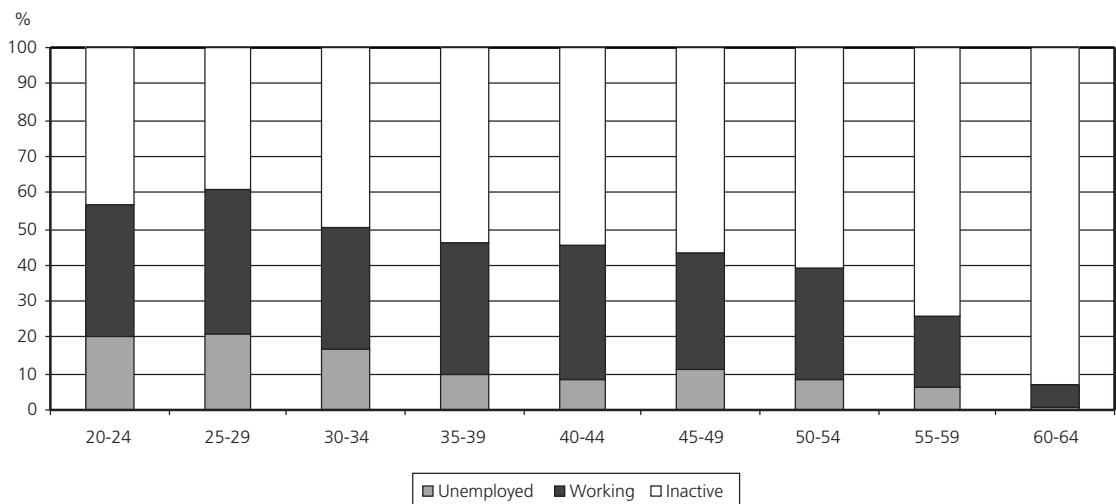
report that they have left a job because of their disability and that they could have remained in work if suitable adaptations had been offered.

It is argued below that the increase in the participation rate of people with disabilities requires a policy based on clear targets for the employment of people with disabilities. In fact, the employment level appears to be the main factor influencing the decision on whether or not to participate in the labour market.

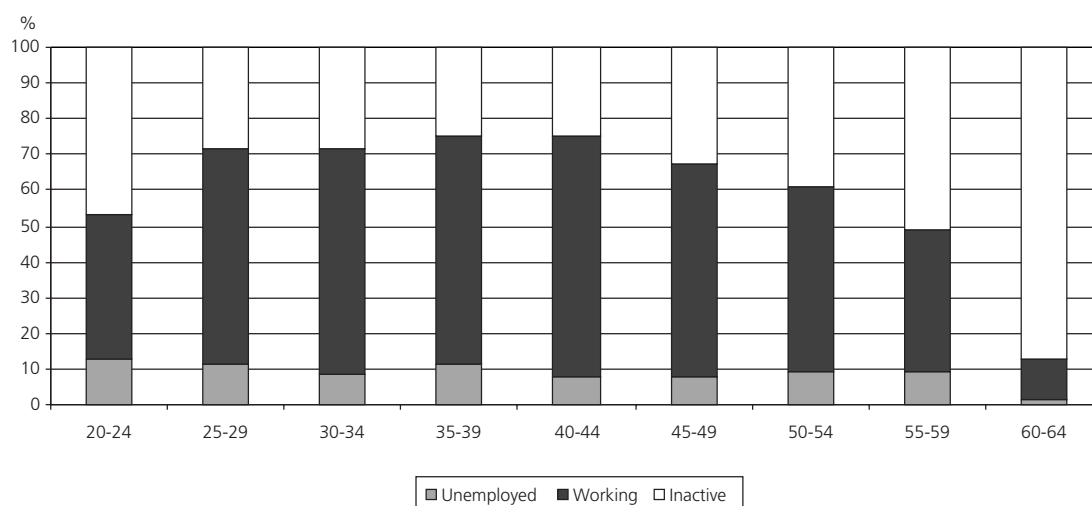
**Figure 15 Inactivity rates by type of disability and age group, EU 1996.**



**Figure 16 Distribution of severely disabled according to economic status and age group, EU 1996**



**Figure 17 Distribution of moderately disabled according to economic status and age group, EU 1996**



Source: Eurostat, 2001. Survey data.

The EU Council of Stockholm put the target for the employment of older workers at 50% for 2010. The preceding figure shows that this rate could be achieved by people with moderate disabilities, but is way above the current rate for people with a severe disability. For the latter a rate of 30% could be a realistic objective.

A European policy aiming to increase the labour participation of people with disabilities and reduce big differences between Member States could study four targets further:

- to reduce the relative disadvantage of people with disabilities in those countries where the employment ratio of disabled people to non-disabled is low;
- to set a target for employing people with severe disability (for example 25% for 2005 and 30% for 2010) and people with moderate disability (for example 45% for 2005 and 50% for 2010);
- to diversify the nature of jobs in countries that have already attained the target, as this could improve further the employment and the activity rate of people with disabilities;
- to strengthen the overall labour market participation, notably for women, in countries with a low overall activity rate, as this could be an attractive factor for women with disabilities too.

The target of 25% for the employment of people with a severe disability will mean that seven countries will have to attain it in a very short time. The target of 45% for the employment of people with a moderate disability will mean that seven countries (not the same seven) will have to attain it in a very short time (see Figure 18 on p. 47).

On the nature of barriers encountered, it is interesting to note that in the United Kingdom 62% of economically inactive people with health problems or a disability have mobility problems. This rate is 33% for economically active people with health problems or disability. The second problem appears to be the ability to lift, carry or otherwise move everyday objects (53% and 27% respectively). Similar results are found in other Member States (N. Meager et al, 1999; S.

Grammenos, 1995). This reinforces the argument that the physical accessibility of work is a prerequisite for any successful integration policy. Furthermore, the previous survey revealed that 34% of economically inactive people with disabilities said that they would like to work compared with only 27% of those with no disability.

The lack of suitable adaptation to the working environment may be an important barrier to participation. In the United Kingdom, 34% of the employed disabled had special working arrangements (notably flexitime) but very few reported that these arrangements were due to their disability or health problem (N. Meager and A. Hibbet, 1999). Information for other countries is scarce, but the European Labour Force Survey 2002, and its ad hoc 'Module on the employment of persons with disabilities', ought to fill this gap.

### **Employment rate of people with illness or disability**

An interesting question for policy is whether the employment of people with disabilities is dominated by specific factors or if it follows the same determinants as general employment. The following figure reveals that the employment rate of people with disabilities is high in countries where overall employment is high. This indicates that general conditions carry more weight than specific conditions linked to illness or disability. This does not mean that the latter are not statistically significant.

Considerable variations between countries are observable. The total employment rate for people with moderate disabilities varies from 27% in Ireland to 54% in Germany, with an EU average of 43%. For those with a severe disability, it ranges from 13% in Spain to 37% in France, with an EU average of 22%.

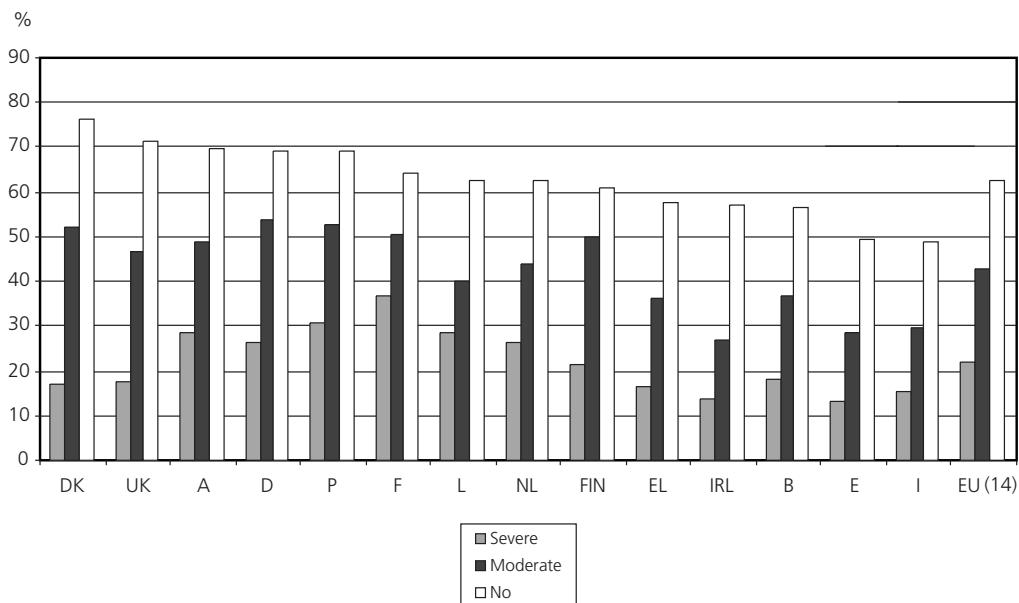
The employment rate for people with a moderate disability is below the European average in six Member States (Belgium, Greece, Spain, Ireland, Italy and Luxembourg). The employment rate for those with a severe disability is below the European average in eight Member States (Belgium, Denmark, Spain, Greece, Ireland, Italy, Finland and the United Kingdom).

The employment ratio of the moderately disabled to the non-disabled is 68% at EU level. But this ratio is only 47% in Ireland, revealing a substantial disadvantage for people with disabilities. At the other extreme it is 82% in Finland, where the situation is relatively much better. The employment ratio of the severely disabled to the non-disabled is 35% at EU level. This ratio is only 22% in Denmark, where the severely disabled are most disadvantaged, but at the other extreme it is 58% in France.

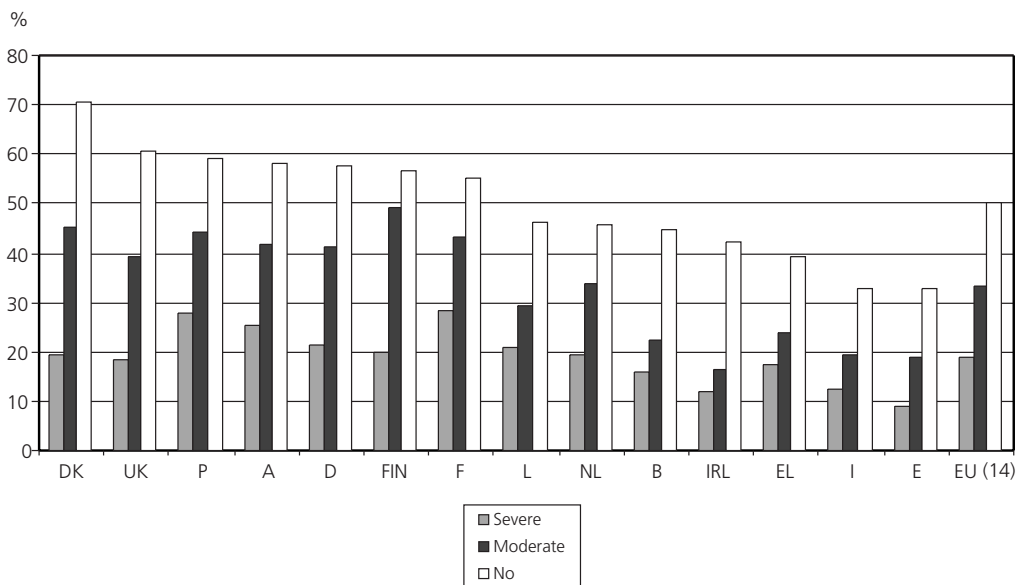
The employment ratio of moderately disabled women to non-disabled women is about 67% at EU level. It is only 39% in Ireland, but 87% in Finland. The employment ratio of severely disabled women to non-disabled women is about 38% at EU level. But this is only 27% in Denmark. At the other extreme it is 52% in France.

In general there is a greater variation between countries in the employment ratio of moderate to non-disabled, compared with severe to non-disabled.

**Figure 18 Total employment rate by country and disability status**



**Figure 19 Employment rate of women by country and disability status**



Source: Eurostat, 2001. Survey data.

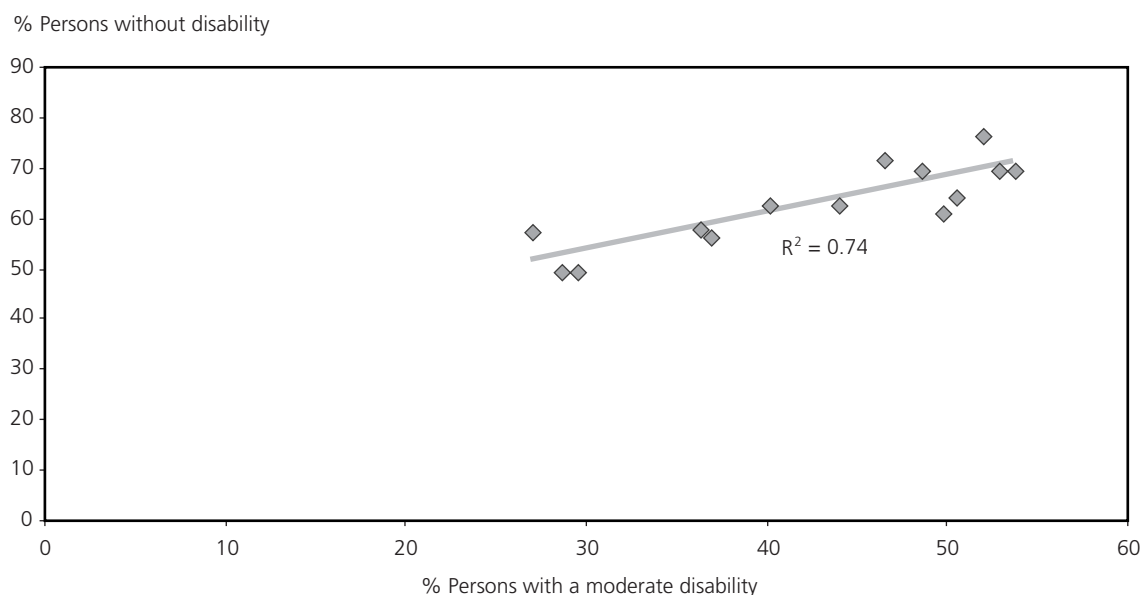
## Work disincentives

### Administrative disincentives

Bureaucracy and administrative inflexibility might be an important barrier to employment. In a labour market characterised by high unemployment rates and discrimination, getting a job and keeping it is difficult. People will risk accepting a trial period if they know that in case of failure they will recover their rights without entering again into a long administrative process. Difficulty in recovering one's rights could be a disincentive to search for employment and certainly for accepting temporary employment.



**Figure 20 Being in work: persons with a moderate disability and persons with no disability (both sexes)**



Source: Eurostat, 2001. Survey data.

The assumption underlying many national laws is that taking a job means a permanent recovery and therefore a need to re-evaluate the degree of disability. Many people face a difficult situation, where they have to convince ‘social security’ of the presence of an illness or a disability even though they are able to work. If they have a degree of disability close to the critical minimum level, a small revision could lead to the total loss of benefit. For example in Greece and Ireland those receiving a disability pension may not work, otherwise they lose their pension.

### Income taxation

The ‘taxation trap’ is when, due to tax levels, working brings a very small gain in income. This can be a strong disincentive, notably for unskilled people without any prospect of high earnings and job promotion.

It is necessary to look at the situation in certain countries in order to clarify this disincentive effect of marginal taxation, beginning with the case of Sweden and Finland, which are representative of many European countries. Consider someone receiving a disability pension, a housing benefit and other allowances. Their income lies between 50% and 75% of an average salary. Suppose that they find a job and improve their earnings but remain in the same bracket for average pay. Their marginal taxation rate will be: 84.4% in Finland and 93.2% in Sweden. This is because people in the lowest bracket receive housing benefit and other allowances that decrease as earned income increases.

For comparison, consider a person with an income between 100% and 125% of an average salary. The marginal taxation rates will be: 54% in Finland and 34.8% in Sweden.

**Table 7 Total marginal taxation for single disability pensioner in 1998**

Income level	50-75% of APW	75-100% of APW	100-125% of APW
Finland	84.4	90.4	54.0
Sweden	93.2	72.7	34.8

In percentage of average pay of a production worker (APW)

Source: NOSOSCO, 2001.

In Belgium beneficiaries of invalidity pensions can add their pension to paid work. This is an incentive to return to work. However, there are only 2% of temporary pensioners (less than one year) and 5% of permanent pensioners (more than one year) receiving a pension and doing paid work (H. Larmurseau and P. Lelie, 2001).

The possibilities are:

- If pensioners gain a small amount of money, this will not change the amount of their pension. They can keep both incomes without any implications in our simplified model.
- Over a certain ceiling, every additional euro of earnings will reduce their pension by an equivalent amount. If the total income is under the minimum taxable income, this will not affect total net income in our simplified case.
- If the total income is over the minimum taxable income, then an additional euro of gross earnings will reduce the pension by a euro. As taxation is higher for work income than for social benefits, total net income decreases.

Consequently, the taxation scheme favours part-time work but not a significant reintegration into the labour market.

The next table presents the interesting situation of an 'inactivity trap' due to marginal taxation. It focuses on the impact paid work could have on a partner's income. Take the case of a married couple without children. Both receive a disability allowance (a means-tested benefit). Their disability rate is high and they are not able to look after themselves. Consequently, they receive an additional integration allowance.

If one partner finds a part-time job, this will reduce their own disability allowance and their partner's. In fact both allowances are means tested. The following table indicates that the general result is a small decrease in total net household income. For the small increase in income shown, there is no change in the integration allowance. However, higher labour earnings may reduce the integration allowance and further reduce total net household income.

## Unemployment

The unemployment rate of people with a moderate illness or disability is about twice the level of those with no disability, while the rate of people with a severe illness or disability is about three

times the level of the non-disabled. If you think that employment is the main road to inclusion in society in Europe, it becomes clear that measures to reduce this discrepancy are urgent.

**Table 8 Taxation for disability pensioners in Belgium**

<i>A married couple without children. Both receive a disability benefit. One partner finds a job.</i>	Before work	With part-time work
Labour earnings	0	7,288
Disability allowance; partner 1	8,461	3,037
Integration allowance; partner 1	2,967	2,967
Disability allowance; partner 2	8,461	4,524
Integration allowance; partner 2	2,967	2,967
Total gross income	22,856	20,783
Total net income	22,856	20,320
Marginal effective tax rate	–	> 100

Source: H. Larmurseau and P. Lelie, 2001.

Inclusion through work has three main benefits for the individual:

- a source of income,
- a contribution to the creation of social wealth and, therefore, recognition of their ‘usefulness’,
- a structuring effect on their time and their life in general.

Consequently, it is not surprising to see that unemployed people with illness or disability often have mental problems. Current policies in some Member States – policies that ensure a minimum income but do not take active measures to integrate the disabled into the labour force – may lead to a deterioration in their mental health.

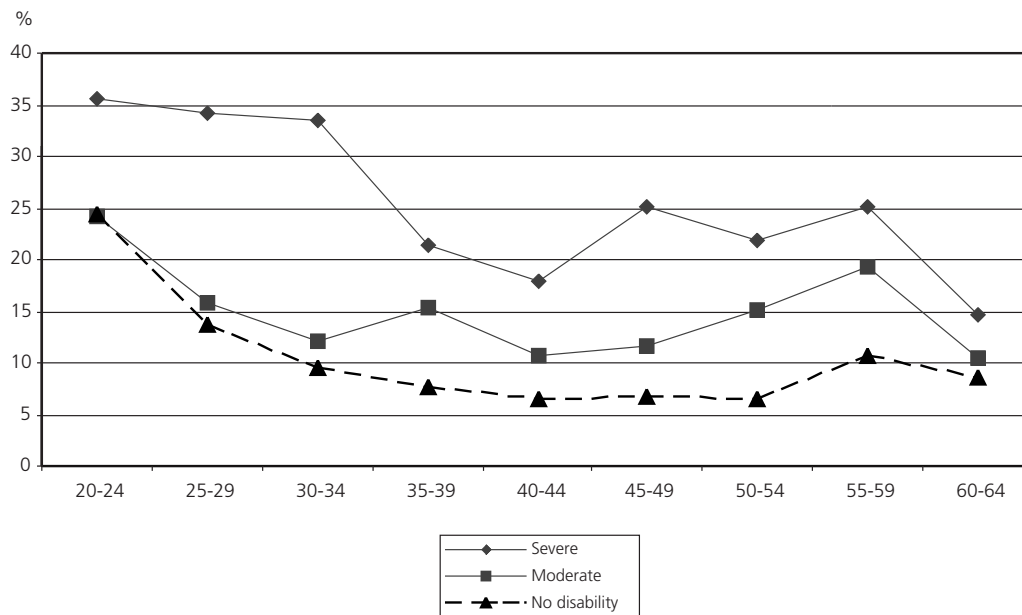
People aged 60 to 64 with disabilities have a lower unemployment rate, indicating a high rate of early retirement.

## Discrimination

Some studies compare the net disposable income (including social assistance benefits) of disabled people with non-disabled people, and conclude that economic discrimination is low. This measure underestimates the real discrimination, as taxation and social policy (means-tested benefits) correct the gap in incomes from working. So the right measure for comparison is the actual wage.

In general, people with illness or disability receive a lower wage compared with the non-disabled. The wage differential between them can be divided into:

- a difference due to a productivity differential, and
- a discriminatory residual.

**Figure 21 Rate of unemployment by disability status and age group, EU 1996**

Source: Eurostat, 2001. Survey data.

Health-related variables are thought to explain part of the productivity differences between groups. However, the results are mixed and relatively small wage differences can be explained by health variables (D. S. Salkever et al, 1997). It is important to note that productivity differences (e.g. a lower education level) may reflect pre-work discrimination.

The discriminatory residual represents the estimated effect of market discrimination. In the absence of labour market discrimination, the wage differential would simply reflect productivity differences. However, the market discrimination masks how much of the wage differential (not explained by productivity differences) can be attributed to overpaying the majority group of workers and how much corresponds to underpaying the minority group (R. L. Oaxaca and M. R. Ransom, 1994).

The underlying idea is that the advantaged workers (the majority group) gain directly from discriminating against the minority group (those with an illness or disability). The wages of the advantaged group are not those they would have received in the absence of discrimination. Similarly, there is a difference between the wages that people with disabilities would have received in the absence of discrimination and their actual wages (see table).

The overpayment that the majority group receives as a result of discrimination is clear in some situations: e.g. a company agreement allowing for exemption from quota obligations, a company practice to fire workers in order to exploit disability schemes, etc.

## Illness, disability and social inclusion

Gross (unadjusted) wage differential	=	Market discrimination		+	Productivity differences (may reflect pre-work discrimination)	
Gross (unadjusted) wage differential	=	Wage advantage	+	Wage disadvantage	+	Productivity differences (may reflect pre-work discrimination)
Gross (unadjusted) wage differential	=	Majority group overpayment	+	Minority group underpayment	+	Productivity differences (may reflect pre-work discrimination)

Source: Drawn from Oaxaca, R. L., and Ransom M. R., 1994.

Some studies<sup>7</sup> indicate that productivity differences are the result of different causes, depending on the ground of discrimination:

- gender (comparing men/women): lack of experience;
- race (comparing black/white, nationals/migrants): lower educational level;
- sexual orientation (comparing heterosexuals/homosexuals): marriage premium;
- illness and disability (comparing non-disabled/disabled): qualifications and health limitations.

Some countries have adopted laws prohibiting wage differentials (Germany, Ireland, Austria) between disabled and non-disabled. However, they remain in certain countries<sup>8</sup>:

- Germany: 35%
- Ireland: 20%
- the Netherlands: 15% to 25%
- Sweden: 6%.

These large differences are surprising and need further study. In what follows only a few possible research directions are presented. In all countries they might especially be related to wage discrimination, lower productivity due to health, education and statistical errors<sup>9</sup>. Specific differences between countries could stem from different employment policies on minimum wages, employment rates for people with severe disabilities, etc.

This situation might be expected, given the fact that those with low economic status are more likely to become disabled. So a bad pre-disability situation is worsened by the occurrence of illness and disability. This has been reported for Germany (R. V. Burkhauser and M. C. Daly, 1998)<sup>10</sup>. However, it is contested. The argument is that those with disabilities who obtain employment have convinced employers that they are capable of meeting the job requirements. So the effect on wages is small (M. L. Baldwin and W. G. Johnson, 2000).

<sup>7</sup> M. L. Baldwin and W. G. Johnson, 2000; R. L. Oaxaca and M. R. Ransom, 1994; D. S. Salkever and M. Domino, 1997; P. S. Thoursie, 2002.

<sup>8</sup> D. S. Salkever and M. Domino, 1997; R. V. Burkhauser and M. C. Daly, 1998; P. S. Thoursie, 2002; European Foundation for the Improvement of Living and Working Conditions, EIROOnline.

<sup>9</sup> R. V. Burkhauser and M. C. Daly, 1998, advance the hypothesis that part of these differences might arise from the fact that cross-sectional data might over-sample "long stayers", i.e. men whose disability occurred long ago.

<sup>10</sup> Baldwin (SEJ) notes that the results of American data show that there are large productivity-standardised wage differentials between disabled and non-disabled men. Differences in physical limitations are an important factor explaining disabled/non-disabled wage differentials, but controlling for differences in physical limitations does not eliminate the wage differences.

Public transfers and taxation reduce this difference, but the wage differential remains the real indicator of discrimination. A policy of non-discrimination ought to abolish these differentials, while social protection ought to focus on general well-being and transfers.

It was noted above that productivity differences may reflect pre-work discrimination. In general, worker's pre-work market investments and endowments are considered as given. But these may be the result of segregation (in education, housing, etc.) and of the discrimination itself.

In a discriminatory society someone with a disability is expected to invest less in human capital (education and training) than someone without a disability. But the expected wage for a given number of school years is lower for a disabled person than for someone with the same education but without a disability. This is the same as the well known criticism that employers focus more on the disability than the potential of a disabled candidate for a job. So discrimination will incline people with disabilities to invest less in human capital. What is seen as a pre-work endowment (initial education and training) is itself determined by discriminatory attitudes.

As noted several times, people with chronic illness or disability do not form a homogeneous group. Different studies (Ferrer-i-Carbonell et al, 2001; M. L. Baldwin et al, 1993) find that people with mental illness are those with most problems in comparison with other types of illness and disability. These studies construct a ranking for different groups of impairments. The results in the following table indicate that nervous and emotional problems (including alcohol and drug problems), and mental illness are the groups with the biggest difficulties. People using an aid to get around, and those with a hearing, seeing, walking or speaking difficulty are the least discriminated against.

The influence of health variables on wage rates is much disputed. However, there is wide agreement that health variables do affect the probability of obtaining a job offer.

Shadow price of health		Loss of wage		
Germany (West, workers)	( <sup>1</sup> )	US	Males ( <sup>2</sup> )	Females ( <sup>2</sup> )
1. Skin conditions, allergies	0.12	1. Difficulty in hearing	0.97	0.98
2. Difficulty in seeing	0.20	2. Difficulty in seeing	0.96	0.98
3. Difficulty in hearing	0.20	3. Difficulty walking	0.95	0.97
4. Migraine, chronic headaches	0.23	4. Difficulty speaking	0.95	0.94
5. Chest, breathing problems	0.40	5. Cannot hear	0.95	0.95
6. Diabetes	0.41	6. Cannot see	0.93	0.96
7. Problems with arms, legs, etc.	0.45	7. Cannot walk	0.91	0.95
8. Epilepsy	0.42	8. Cannot climb	0.90	0.95
9. Alcohol, drugs	0.43	9. Missing legs, feet, arms, hands or fingers	0.87	0.83
10. Heart, blood	0.47	10. Cannot lift and carry or climb	0.77	0.86
11. Nerves, anxiety, depression	0.49	11. Nervous or emotional problems or alcohol or drug problems	0.75	0.90
12. Stomach, liver, kidney	0.57	12. Mental illness	0.74	0.85
(1): Equivalent income variations. The subjective cost of health loss increases (from 1 to 12).		(2): Ratio of wage offers with impairments to wage offers with no impairments. Wage loss increases (from 1 to 12).		
Source: Ferrer-i-Carbonell et al, 2001		Source: Baldwin et al, 1993.		

Simon et al (H. Whiteford, 2001) reviewed the literature on the impact of depression on work productivity. They concluded that productivity gains, following effective treatment of depression, could by far exceed direct treatment costs. Compared with other conditions, workers with mental disorders are more likely to go to work but perform beneath their best. US data showed that treatment for migraine, anxiety and depression resulted in the greatest long-term percentage improvement in productivity. Similarly, in the McDonnell-Douglas programme, adequate treatment for mental illness reduced work days lost by 25%.

## Characteristics of people with a chronic illness or disability

Analysis of the methods and the results of several surveys indicate that at European level:

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

For the granting of benefits, 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 expected to be much lower (6% of the working-age population).

Those with an illness or disability do not make up a homogeneous group. Differences in age and the nature of disabilities reveal important differences in the type of assistance required. Often people think of illness and disability as if they were congenital. In fact they are life events that could be avoided or delayed over the course of life. Sickness, lifestyles involving high risk, work accidents and socio-economic factors either separately or in combination generate a process, in which the rate of chronic illness and disability moves progressively from 5% to 40% at retirement age.

Increasing disability-free life expectancy requires an active policy of prevention, notably during the economically active period. It also requires an improvement in the living conditions of the most disadvantaged. There are about 25 million adults in the European Union who have a severe chronic illness or a disability. About 15 million need the help of a third person to carry out the basic tasks of normal life (bathing, dressing, feeding oneself, cooking, shopping and housekeeping).

People are living longer and this increases the risk of long-term care needs. The viability of the social protection system has been questioned and new instruments have been adopted in some countries.

## Social determinants of health

Most studies try to assess the direction of the causal relation between income and health or disability. On the one hand, individuals with higher income may have better access to health care services and hence prevent chronic illness and disability. On the other hand, health problems may affect the individual's productivity and hence work earnings. Medical expenses further reduce available income.

A survey of the literature indicates that a number of factors determine health and disability. The following seem particularly important:



- absolute income and relative income;
- education and lifestyles;
- employment status;
- job insecurity;
- social norms (for mental health).

However, there is a big debate about the magnitude of each factor and its contribution to illness and disability. Higher education for some means better working conditions, for others healthy attitudes, and, finally, for others it means higher income. In the first case policy ought to focus on working conditions, in the second on preventing high-risk behaviour and in the latter on medical care.

Different studies find that certain groups accumulate several disadvantages and present a high risk of chronic illness and disability. These groups are the poorly educated, those with a low income and the unemployed. So it is important to monitor trends (in inequalities) in the morbidity and disability of these socio-economic groups. This ought lead to better prevention or to policies that prevent further deterioration of illnesses and disabilities.

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 WHO considers that the drug use situation in Europe is deteriorating. The European Commission, in its report on social inclusion (2001), notes that mentally ill people and drug and alcohol abusers experience particular integration problems and face an especially high risk of persistent poverty.

Different studies find that people with mental problems are those with most difficulties in comparison with other types of illness and disability. So it is desirable to monitor mental health problems such as depression, stress and drug abuse.

Many studies find that blue-collar workers have a higher incidence of disability. This raises the question of the contribution of work accidents and occupational diseases to the rate of chronic illness and disability. Flexibility has been put forward as a significant factor behind physical accidents and higher rates of mental health problems. The adoption of high-performance practices seems correlated to a dramatic increase in occupational injuries and illnesses in certain countries.

In general, companies do not suffer the social consequences of bad working conditions. Only recently have some countries imposed financial costs on companies with a high rate of accidents. The imposition of fines or differentiated premiums on companies with bad accident records is still open to debate.

Improving working conditions requires a permanent dialogue between the 'social partners'. Their involvement is a prerequisite for the reduction of work accidents and occupational diseases.

### **Social exclusion**

The traditional approach, built on a causal relation regarding impairment, disability and handicap, has been influenced by a rights-based approach. The civil rights approach maintains that disability is a restriction on activity caused by a contemporary social organisation that takes little or no account of people who have physical impairments.

The disability movement has highlighted the interaction between individuals' impairments and their social and physical surroundings. By doing so it has demonstrated how society has imposed physical and attitudinal barriers. It stresses the discriminatory barriers in society and argues that society must be modified to include and accommodate the needs of everyone, including people with disabilities.

This has initiated a new approach of accommodation and the elimination of barriers that were limiting people's functioning and creating a disability. The diffusion of this approach to all sectors of society and its introduction in the design of policies for the provision of goods, services and infrastructures ought to favour the inclusion of everyone in social and economic life.

Social exclusion is a multidimensional phenomenon. The European Commission considers that employment is the key route to integration and social inclusion: unemployment is the major factor in exclusion. However, social exclusion goes beyond issues of unemployment and access to the labour market. It calls for attention to education, training, access to public and private services, etc.

Several indicators reveal that those with illnesses or disabilities suffer from poverty. Young people with disabilities appear to be the most vulnerable. So it is important to see whether this is the result of lack of adequate support or of barriers to the access of certain benefits.

### **Barriers**

Autonomy is the ability of people to make decisions for themselves and to act on them. A restriction or a dependency may arise and restrict the extent of choice. In some cases restrictions can be lifted by society, in other cases the dependent person needs help from others to lead a normal life. Support in these cases includes personal assistance, information, housing, education, access to the environment and to the political arena.

The problem with the provision of services is that people with disabilities are far too often still seen solely as the objects of care. As a result disability policy is regarded as a matter of providing care and not as a matter of democracy and equal rights. Applying a disability perspective to our thinking means starting from the understanding that different people have different needs. Disability is just one of the differences in our populations. The same rights can be met in different ways according to individual needs.

The approach to disability endorsed by the European Union considers that barriers are a significant impediment to participation in society and that accessibility and mobility issues ought to be seen in the light of equal opportunities and the right to participate.

Despite national and European policies several obstacles remain, notably those relating to physical barriers, legal and administrative barriers, new technologies and attitudes. New technologies present new opportunities for new technical aids but at the same time they may create barriers in other areas. Finally, perceptions and mental attitudes raise obstacles that need a long-term approach to their removal.

Rules on standardisation, public procurement, provision of services, etc. could be considered by the state. Their object should be to enable people with disabilities to use the same goods and services as everybody else. Initiatives taken by some countries could be considered and replicated in others.

Rules favouring accessibility ought to be seen not as a cost but as an investment that reduces the need for help and makes it easier for people to manage their own lives. Both these elements reduce the number of services that have to be provided and thus bring long-term benefits to society.

Many children are still excluded from mainstream schools merely on the grounds of restricted mobility, sensory impairment or learning difficulties. All too often children with disabilities are confined during their school years (and even beyond) to institutions that, while providing special care, nonetheless isolate them and give them drastically reduced opportunities or none at all for mainstream social engagement.

Special education in closed institutions further isolates children from their families and the rest of society. Policy-makers have to take into account both educational needs and the provision of services that might prevent their marginalisation.

### **Labour market issues**

The non-participation of people with disabilities in the labour market is almost twice as high as non-disabled people. The difference between the moderately disabled and the non-disabled is relatively small. Some inactive people are not in the labour market, not because their disability is particularly severe, but because they are not offered the necessary adaptation or technical aids at work. In fact many inactive people report that they could have remained in work if suitable adaptations had been offered.

Non-participation increases drastically for everyone after the age of 50. This poses the general problem of older workers' participation and its link with health. In fact if pressure is put on disabled workers to stay at work, this could exacerbate further the symptoms and problems already experienced in their jobs. Policies aiming to increase the participation of older people in work must avoid turning moderate disabilities into severe ones.

A European policy aiming to increase the number of people with a disability in work ought to fix realistic targets by taking into account the differences between people with severe and with moderate disabilities. An interesting question for policy is whether the employment of people with disabilities is dominated by specific factors or if it follows the same determinants as general employment. It seems that the employment rate of people with disabilities is high in countries

where overall employment is high. This indicates that general conditions dominate specific conditions linked to illness or disability.

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.

Work disincentives are strong in certain countries. If you accept a job, you might lose your disability benefit. A difficult process to recover your rights could be a disincentive to look for work and certainly to accept temporary employment. Another obstacle is the 'taxation trap'. This is when, for tax reasons, supplementary work brings very small gains in income. This may constitute a strong disincentive, especially for unskilled people.

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. Considering that employment is the main route to inclusion in our societies, the urgency of measures that reduce this discrepancy is clear.

Some countries have adopted laws prohibiting wage differentials between the disabled and the non-disabled. However, differentials between work earnings remain high. The wage differential between those with illnesses or disabilities and the non-disabled may be divided into a productivity difference and a discriminatory residual. It is important to note that productivity differences (e.g. a lower education level) may reflect pre-labour discrimination.



# Part 2

## Overview of national and European policies

Part 2 is a critique of the main policies adopted by the European Union and the Member States. In each case the main policies (legislation, programmes, etc.) are presented, as well as the debate around them. At the end of Part 2 conclusions and policy recommendations are given. The goal is to provide not a list of existing measures, but the rationale behind each action. This part constitutes a guide for any policy-maker who wants to learn from past experience and develop new measures. For each policy instrument the main lessons from past experience are extracted, and its effectiveness in tackling current and emerging problems.

First anti-discrimination policies are examined, in the light of how they could evolve in the coming years. Policies on independent living are relatively more consensual but there are strong differences between Member States. They raise problems strongly related to the family, to the right to live as every other citizen, and so on. Policies on social security and social protection are characterised by a heated debate. The technicalities of the debate often hide underlying dogmatism. A review of the different policies reveals major differences between the Member States.

The next chapter presents employment measures, analysing differences and similarities across Member States. Measures to re-integrate disabled people into work are shown, primarily in terms of companies' responses to these challenges.

The chapter on education considers a selection of innovative initiatives to integrate children into mainstream schools. The evaluation of national programmes is a precondition for the success of future policies. The presentation is non-technical and the interested reader will find more information on methodology in the relevant references. Part 2 concludes with a look at the role of different actors (social partners and NGOs) in the implementation of European and national policies and their contribution to the cohesiveness of these policies.



# Anti-discrimination provisions

# 7

The Council, in its Resolution of 20 December 1996 on equality of opportunity for people with disabilities, invited the Member States to adopt measures for ‘empowering people with disabilities for participation in society, including the severely disabled, while paying due attention to the needs and interests of their families and carers’.

Empowering people with disabilities requires a change in the way they are treated. A rights-based approach means that the ability of the disabled to exercise their rights as human beings effectively is reinforced. The individual right to make choices is a pre-condition for any integration measure. The necessary policy measures will follow, as a second step, to help the disabled implement their choices.

## Constitutional provisions

All Member States except one have constitutional and ordinary laws on the right to equality and the prohibition of discrimination. The United Kingdom does not have a written constitution but its unwritten constitution prohibits discrimination (European Commission, 1999).

The following table presents the constitutional instruments adopted in some Member States to ensure that all people with disabilities can exercise the same rights and are under the same obligations as others. The table does not include countries that do not make an explicit reference to the disabled, even if they could be included in more broadly defined groups. For example, the courts have ruled that the different grounds of discrimination enumerated in Article 1 of the Dutch constitution cover disability. Also Italian courts have ruled that disability could be a reason for discrimination according to Articles 3, 4 and 38 of the constitution.

**Table 9 Explicit reference to chronic illness and/or disability in the constitution**

Germany	Greece	Spain	Austria	Portugal	Finland	Sweden
Constitution Art. 3	Constitution Arts. 21 & 22 Art. 23 § 6	Constitution Arts. 14 & 49	Constitution Art. 7	Constitution Art. 71	Constitution Anti-discrimination clause (Preamble)	Instrument of Government Chapter 1, Section 2
Nobody should be disadvantaged because of their disability.	Those who suffer from incurable physical or mental sickness have a right to special care from the state.	Spanish courts interpreted Article 14, referring to grounds of discrimination, as including disability.	No one may be disadvantaged by disability.	The disabled enjoy the same rights ... except to the extent that their disability renders them unfit to exercise or perform them.	Nobody should be put in a different position because of ... their state of health or disability.	The public institutions shall counteract discrimination on grounds of ... disability, etc.
(Other laws define a ‘social right’.)	People with disabilities have the right to benefit from measures that guarantee autonomy, professional integration, etc.	The state will carry out a policy of treatment, rehabilitation ... of the physically, sensorially and mentally handicapped, etc.	Ensure equal treatment in all fields of daily life.	The state should develop a national policy and support citizens with disabilities.	Reference to ‘social rights’.	

Sources: National constitutions.



Most are guiding principles for the legislator and the policy-maker. When appearing before national tribunals, these provisions are of little help to people with disabilities, even in countries where there is specific anti-discrimination legislation.

In some countries prohibition of discrimination is specified in labour law. As indicated below, the new EU anti-discrimination Directive is going to bring large changes in this area.

### **Anti-discrimination laws**

The Treaty of Amsterdam of 2 October 1997, inserted Article 13 into the Treaty of Rome and so extended significantly the domain of Community law. Article 13 of the Treaty provides the Community with specific powers to take action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.

The Council Directive 2000/78/EC of 27 November 2000, establishing a general framework for equal treatment in employment and occupation, constitutes a major step in the development of anti-discrimination policy. The Directive prohibits any direct or indirect discrimination based on religion or belief, disability, age or sexual orientation with regard to employment and occupation.

It is a 'horizontal Directive' tackling different grounds of discrimination. By comparison the Council Directive 2000/43/EC, implementing the principle of equal treatment between persons irrespective of racial or ethnic origin, is a 'vertical Directive' as it covers one target group but different aspects of economic and social life. From this point of view the race Directive covers more areas (e.g. access to services and education).

The Directive does not aim to achieve identical results for people with disabilities, as a quota system in the employment area does. It aims to ensure that people with disabilities enjoy the same chances as others to achieve certain results. In fact, the Directive states that while aiming at ensuring full equality in practice, the principle of equal treatment shall not prevent any Member State from maintaining or adopting specific measures to prevent or compensate for disadvantage linked to religion or belief, disability, age or sexual orientation. Consequently positive action aims to prevent or compensate the disadvantage and contributes towards equal results.

Anti-discrimination laws already existed in the United Kingdom, Ireland and Sweden (see the following table). All these initiatives have drawn on the experience accumulated by the Americans with the Disabilities Act (ADA).

The Directive does not define 'disability'. Member states have to transpose the Directive into their national legislation. However, some other elements in the Directive may be useful in cases of dispute. When Member States transpose the Directive into their national law, they are expected to modify existing national laws in order to conform to it.

An important aspect of the new Directive, in comparison with existing laws, is the burden of proof. The difficulty of proving discrimination was an important factor explaining the weakness of previous legislation. The Directive has 're-equilibrated' the burden of proof.

Member States with pre-existing, specific anti-discrimination law were Ireland, Sweden and the United Kingdom. In the following sections, the main provisions of these national laws are outlined, as well as the equivalent law in the United States for comparison.

### **The United Kingdom**

The Disability Discrimination Act (DDA), 1995, introduced measures to make it unlawful to discriminate against disabled people in the following areas:

- employment;
- access to goods, facilities and services; and
- the sale, letting and managing of premises.

In addition the Act required schools, colleges and universities to provide information for disabled people. From this point of view the Act is broader than the EU Directive. The Act defines a disabled person as someone who has a physical or mental impairment that has a substantial, long-term and adverse effect on their ability to carry out normal day-to-day activities. This definition is very restrictive and is expected to be modified following the adoption of the EU Directive establishing a general framework for equal treatment in employment and occupation.

Employers have a duty not to treat a disabled person less favourably than others for a reason relating to disability, without justification. A justification must be both material to the particular circumstances, and substantial. The effectiveness of the DDA is monitored. This has shown that disabled people have used the DDA to fight against discrimination. Cases have been brought to court and won.

Different surveys report that the most common form of discrimination felt by people with disabilities relates to the recruitment process (N. Meager and A. Hibbett, 1999)<sup>11</sup>. However, relatively few cases reach court, even if the most common court cases relate to dismissals. It is felt that the burden of proof of discrimination has been particularly acute in recruitment cases and partly explains the relatively low number of such cases.

People with mental health and psychological problems are over-represented in cases heard. They are followed by people with sensorial impairments and disabilities connected with the arms or hands. By contrast, people with chronic illness are strongly under-represented (N. Meager and B. Doyle, 1999). Public administration seems to be, both in absolute and in relative terms, the sector of the economy where there is most discrimination.

Questions relating to the definition of disability have been at the centre of a significant number of cases, notably (N. Meager and B. Doyle, 1999):

- what constitutes a mental impairment for the purpose of the Act;
- the interpretation of 'normal day-to-day activities' and the impact on work;
- aspects relating to 'substantial and long-term adverse effects'.

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<sup>11</sup> The Baseline Disability Survey reveals that the most common form of discrimination relates to the recruitment process. The disability rights Commission reported that it had taken over 144,000 calls on its Helpline from people with disabilities, from April 2000 to March 2002 (Disability World, 2002). The majority of calls related to the Disability Discrimination Act. Of these 57% were concerned with employment issues and 30% were concerned with goods, facilities and services.

The Disability Discrimination Act is expected to be modified following the adoption of the EU Directive for equal treatment in employment and occupation. The EU Directive means that all employers will be covered by anti-discrimination laws, including those smaller ones who are currently exempt.

### **Ireland**

The Irish Employment Equality Act, 1998, which came into force on 18 October 1999, prohibits discrimination in employment on nine grounds, including disability (gender, marital status, family status, sexual orientation, religion, age, disability, race and membership of the Traveller community).

The legislation gives protection to employees in both the public and private sector irrespective of the size of the organisation. Employment in the Defence Forces, in the police and in the prison services is, however, excluded from the disability provisions of the Act. The Act applies to all areas relevant to employment, including access to employment, conditions of employment, training and promotion.

This Act affords protection against discrimination to people with disabilities who are fully competent, capable and available to do the job. It provides for the reference of disputes to independent statutory bodies, namely the office of the Director of Equality Investigations and the labour court. The Act provides an individual right of redress. Currently the Employment Equality Act, 1998, and the Equal Status Act, 2000, are under review to see whether there is a need to modify them in accordance with the EU Directive.

### **Sweden**

In Sweden the law, which came into force on 1 May 1999, prohibits discrimination against people with disabilities on the labour market. More precisely, it prohibits discrimination due to disability against job applicants or employees. The law also covers decisions on promotion, training for promotion, pay and employment conditions and dismissals.

The law defines disability in a wide manner, saying that the disabled are people with durable physical, mental or learning limitations to their ability to function. It includes limitations that the person in question has had from birth or that appeared later or can be expected to appear later (e.g. cancer, MS and HIV). Both direct and indirect discrimination are prohibited.

Direct discrimination refers to a situation where a disabled person is treated less favourably compared with how a person without the disability has been or would have been treated in a similar situation. To determine if a similar situation exists, a comparison must be made between the disabled person and one or more other people without a similar disability. However, an actual comparison is not required; a hypothetical one is sufficient. The law also demands investigations and other more forceful measures to be taken by an employer in cases of harassment of an employee due to his or her disability by an employer, a manager or a colleague.

The labour unions are supposed to be the first-choice enforcers of the law prohibiting discrimination in working life against people with disabilities. They have the right to negotiate with

the employer and bring the matter to the Swedish Labour Court as the representative of the employee. If the labour union does not act or does not wish to act, the Disability Ombudsman has the right to become the representative of the disabled employee or applicant, first in negotiations and then in court.

The Office of the Disability Ombudsman is a government authority that monitors the civil rights and special interests of people with disabilities. The Ombudsman works to achieve the general objectives of disability policy: full participation and equality for people with disabilities. The majority of cases treated by the Ombudsman have concerned discrimination in salary or employment benefit, but others have concerned denied employment, transfer, inadequate management, dismissal and harassment. The sanction for breaking the law is always an economic remedy.

### **The USA**

The Americans with Disabilities Act (ADA) is a civil rights law that protects individuals with disabilities in a similar way to those protecting individuals on the basis of race, sex, national origin, age and religion. It supports equal opportunities for individuals with disabilities in public accommodation, employment, transportation, state and local government services, and telecommunications.

A survey done by S. L. Harlan and P. M. Roberts (1998), finds that employers are reluctant to implement the Act and that employees are discouraged from making formal requests or persuaded not to pursue their claims. Also there is very little use of unions. However this finding may not be relevant to EU countries where the role of trade unions is much more important.

### **The role of social partners**

The EU Directive provides that the 'social partners' can be involved in the implementation of the Directive in conformity with their national traditions and practices, notably through:

- the monitoring of workplace practices, and
- the conclusion of agreements laying down anti-discrimination rules in their field of competence.

### **Reasonable accommodation**

A duty of reasonable accommodation is an interesting instrument for the integration of people with disabilities into ordinary environments, in order to avoid them clustering in specific, parallel networks (sheltered employment, special education, separate services, etc.).

A duty of reasonable accommodation acknowledges that integration requires effort from both the person with a disability and society. It requires employers to examine the possibility that the 'disability' is located in the work environment and to provide alternative job designs (S. L. Harlan et al, 1998).

**Table 10 Anti-discrimination legislation in the EU and the USA**

	Ireland	Sweden	UK	EU	USA
Law	Employment Equality Act, 1998.	Law on discrimination in work life of persons with disabilities, 1999.	Disability Discrimination Act, 1995.	Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation.	Americans with Disabilities Act (ADA), 1990.
Definition	Total or partial absence of a person's bodily or mental functions. Presence of organisms causing, or likely to cause, chronic disease or illness.  Malformation, disfigurement.  Condition resulting in a person learning differently from a person without the condition.  Disturbed behaviour.  Includes a disability previously but no longer existing, or which may exist in the future or which is imputed to the person.	Enduring physical, mental or learning limitation in terms of functional capacities that have occurred at birth or later.  Learning limitations.  (Enduring limitations) that can be expected to occur as a consequence of injury or disease.	A physical or mental impairment that has a substantial and long-term adverse effect on ability to carry out (listed) normal day-to-day activities.  Disfigurement (if severe).  Learning disabilities.  Mental illness (ICD cases).  Includes those who had a disability in the past. Excludes currently diagnosed future disabilities.	The Directive has adopted a 'universal right' approach which implies a broad definition.	Physical or mental impairment that substantially limits one or more major life activities (including working activities).  Disfigurement.  Learning disabilities.  Psychological disorders & mental illness.  Those having a record or those regarded as having a physical or mental impairment.
+ : included - : excluded	+ drug addiction. + alcoholism.		- addiction to substances. - addiction to alcohol.	Rather broad definition. + statistical discrimination.	+ emotional illness. - if devices mitigate impairment.
Main areas	Employment. Vocational training. Services (Equal Status Act, 2000). Property (Equal Status Act, 2000).	Employment. (Vocational training selection).	Employment. Training and education. Provision of goods and services. Premises.	Employment. Vocational training.	Employment. Job training. Services (reasonable access) Transport & tele communications.
Evaluation of competences	Take into account special assistance and facilities.	No discrimination directly or indirectly by reference to disability	'Day-to-day activities' does not include work. Employment provisions apply to employers with ≥ 15 employees.	Essential functions. Take into account national measures for adapting the work place.	Ability to perform the functions (essential elements) of the job. Employers with ≥ 15 employees.
Obligation	Reasonable accommodation.	No.	Reasonable adjustments.	Reasonable accommodation.	Reasonable accommodation.
Maximum cost	Nominal cost.	-	If the employer brings justifications.		Disproportionate burden. Undue hardship.
Control mechanism	Office of the Director of Equality investigations.	Disability Ombudsman (monitors the implementation).	Disability Rights Commission (monitors the implementation).	Ensure judicial/ administrative procedures for the enforcement.	
Trends	Equal Status Act adopts the same definition. The Employment Equality Act is under revision.		Final rights of access for services will come into force in 10/04.	Member States shall adopt the necessary laws by 2/12/03.	The terms 'impairment' and 'substantial' tend to dominate in practice.

Sources: National laws and EU Directive.

The terms 'job adaptation' and 'accommodation' play important roles and it is useful to define their meaning. Job adaptation is the adaptation or redesign of tools, machines, workstations and the work environment to an individual's needs. It may also include adjustments in work organisation, work schedules, sequences of work and in breaking down work tasks into their basic elements (ILO, 2001). Job adaptation includes adjustment and modification of machinery and equipment and/or modification of the job content, working time and work organisation, and the adaptation of the work environment to provide access to the place of work and to facilitate the employment of individuals with disabilities (ILO, 2001).

The EU Directive provides that 'in order to guarantee compliance with the principle of equal treatment in relation to persons with disabilities, reasonable accommodation shall be provided ... unless such measures would impose a disproportionate burden on the employer'.

In terms of effective and practical measures to adapt the workplace, the Directive recommends:

- adapting premises and equipment;
- patterns of working time;
- the distribution of tasks;
- the provision of training or integration resources.

It is important to note that the Directive limits the obligation to a 'reasonable accommodation' and that it has to avoid a 'disproportionate burden on the employer'.

### **The United Kingdom**

The employment provisions of the Disability Discrimination Act (DDA) apply to employers with 15 or more employees. These provisions protect disabled employees and job applicants from discrimination and place a duty on employers to make reasonable adjustments if their premises or working arrangements substantially disadvantage a disabled person.

The Disability Discrimination Act is expected to be modified following the adoption of the EU Directive for equal treatment in employment and occupation. The Directive means that all employers will be covered by anti-discrimination laws, including those smaller employers who are currently exempt.

The Act covers:

- altering work hours;
- transferring a person to an existing vacancy;
- allocating some duties to another employee;
- changing the place of work (e.g. to one more accessible);
- time off for rehabilitation, treatment;
- providing or adapting equipment;
- providing a reader or interpreter.

A study of cases brought to court reveals that in certain cases a conflict arose between the obligation of 'reasonable adjustment' and the employer's other obligations (e.g. health and safety).

Service providers are encouraged to plan for further duties, which are due to come into force in 2004. These duties will require service providers to make reasonable adjustments to physical barriers to their services. This could mean, for example, installing a permanent ramp so that wheelchair users can get into premises with steps.

### **Ireland**

The Irish Employment Equality Act, 1998, affords protection against discrimination to people with disabilities who are fully competent and capable and available to do a job and require no special treatment or facilities at work, or who will require a reasonable accommodation that is cost-free or at only a nominal cost to the employer. In the case of a person with a disability, being fully capable of doing a job may include doing it with the assistance of special treatment or facilities.

### **Sweden**

When employing or promoting a disabled person an employer is obliged by law to make reasonable adjustments and provide a functional environment. However, the definition of 'reasonable' is not very precise. Measures that can be required are, for example, work organisation, work assignments or work schedules. So a certain duty to adapt the workplace is placed on the employer in individual cases. In determining what is reasonable, various factors should be taken into account. These include the cost of the measure, the expected effects, other types of inconvenience for the employer and the expected length of the employment.

The law is expected to be modified in order to conform to the EU Directive.

### **The USA**

The Americans with Disabilities Act provides that an employer has to make reasonable accommodations to the physical or mental limitations of qualified individuals unless the employer can demonstrate that these would impose an undue hardship on the operation of the business. This includes job restructuring, part-time work, reassignment to a vacant position and provision of training tools. Work schedule demands are the most frequent.

### **Comparisons**

An employer is not obliged in any country to make a workplace accessible to all potential employees with disabilities. All depends on the specific circumstances of the relationship between the employer and the job applicant. By contrast laws on accessibility do impose an obligation to provide access to all potential *users and customers*.

The principle of reasonable accommodation implicitly rejects the notion that organisations are neutral work environments in which the terms and conditions of employment are natural outcomes of technological and economic forces beyond the control of employers (S. L. Harlan and P. M. Roberts, 1998). It follows that an employer must know of a disability before the duty can be triggered. Whether such knowledge needs to be express or may be constructively attributed to the employer is unclear (R. Whittle, 2000).

Regarding the cost of accommodations, analyses of similar cases in Canada indicated that this cost amounted usually to less than 1,000 Canadian dollars (C. Raskin, 1994). A survey done in the USA, by S. L. Harlan and P. M. Roberts (1998), found an average cost per employee of US\$200-233, while J. A. Mello (1995) noted that in the majority of cases the cost was between US\$50 and US\$500.

On the nature of the accommodations, some cases (for example mental illness) could require accommodation that is less precise than cases of physical impairment. In these latter cases, the needs are often quite precise: for example, technical aids to hear or see better (Baldwin et al, 1993). The number of claims brought and completed in 1997 under the DDA in the United Kingdom amounted to 440 (N. Meager and B. Doyle, 1999). About 5% of these were related to reasonable adjustment, which is a relatively low share. In this context health and safety issues were most commonly cited by employers.

US Federal Courts have ruled on many aspects of reasonable accommodation under the ADA, notably (S. L. Harlan et al, 1998):

- job leave is recognised as reasonable accommodation;
- the employer is not required to lower standards or remove essential job functions;
- employers do not have to make accommodations that would change the essential functions of the job.

The British Council of Disabled People maintains that if there are costs to addressing discriminatory issues and practices, then, within the concept of reasonableness, they will fall on the employer. To the extent that the cost is not considered reasonable, then the government has a duty to make a grant to make up the difference.





# Policies promoting independent living

## Home help and long-term care

Table 11 presents the conditions imposed by Member States in the provision of services promoting independent living (notably living at home). By contrast with the definitions regulating social security and employment measures, the dominant aspect here is not impairment but the idea of a 'need' or of 'assistance'. During the assessment process most Member States explicitly use criteria related to the activities of daily life. Medical criteria are only part of the assessment process and do not seem to be the dominant element (except in Ireland and Greece).

The need for assistance from a third person is often a critical element. In fact related allowances aim to compensate for the extra costs incurred to live independently. In the Nordic countries and the United Kingdom, these schemes are managed by local authorities and are often accompanied by the provision of services. For example special transport services and meals are provided either directly by the municipality or indirectly through a private company.

A relatively new instrument in the care of the disabled is the so-called client-linked budget in the Netherlands. This incorporates the principles of demand-driven care, freedom of choice, custom-made care and the promotion of autonomy. This subsidy scheme came into effect on 1 January 1996. It enables people with a mental disability, who have a referral for care, to apply for such a budget. With it they can buy the required care and supervision themselves, or have others buy it on their behalf. This means that they can choose who provides care and when. This offers them more freedom and flexibility in arranging their daily lives. These budgets constitute a demand-driven supplement to existing schemes for the provision of care, which are usually supply-driven.

Beneficiaries are usually all adults with long-term care needs, but specific schemes exist for the elderly in some countries. As noted earlier, the share of elderly people in the total population is increasing and is expected to increase further in the coming years. So the number of people needing care and assistance is expected to grow rapidly. This will put some pressure on the financing of such schemes.

In Germany, Austria, Luxembourg and Belgium (Flanders), old age dependency is considered a risk that has to be insured against. It is interesting to note the active role of social partners in the creation and financing of such schemes. Finally, in Greece, Spain, Italy and Portugal long-term care is part of social assistance.

Recent policies favour living at home rather than in institutions. This raises the question of who is going to provide long-term care and assistance, and whether services provided or paid by public authorities are sufficient to meet the growing demand. The European Community Panel (1994) reveals that the proportion of people aged 80 plus who live with their children or a relative is:

- more than 35% in Greece, Portugal and Spain;
- between 2% and 5% in the Nordic countries and the Netherlands; and
- at an intermediary level in France, Germany and Belgium.

Most of the informal carers are women (about 70-80% in Austria, France and Sweden). This could have an adverse effect on the integration of women into the labour market. Currently some

countries provide special allowances to those providing caring for a dependent person (notably France, Germany, Italy, Spain, Sweden and the United Kingdom). In general the allowance aims to compensate for loss of earnings, but in certain cases it also allows acquired labour rights to be maintained.

A series of studies by the Foundation concludes that assistance for family carers should form an integral part of the objectives and responsibilities of services and organisations looking after elderly people (European Foundation for the Improvement of Living and Working Conditions, 1998).

Policies to take people out of closed institutions and to promote living at home are followed in all European countries. For example:

- In Denmark special funds have been allocated to build housing for people under 60 with physical disabilities.
- Greece has developed efforts to integrate people with mental health problems, living in closed institutions, into special, independent or semi-independent accommodation.
- In the Netherlands the 'Home and Care incentive scheme' promotes combinations of housing and care service provision to enable people with illness or disability to live independently.
- Sweden follows its policy of de-institutionalisation and moving people into residential housing or into homes of their own.
- In the United Kingdom the Scottish authorities aim to increase the number of people with learning disabilities living at home or in a 'homely' environment.

### **Design for all**

The basic idea behind the concept of 'design for all' is that articles for everyday use – and other similar products, buildings, indoor and outdoor environments, IT products and services – should be accessible and functional for everyone. Design for all is a concept that includes, at the design stage, the needs of the maximum number of potential users of a product or service.

The Commission states in its Communication on a Barrier Free Europe that it will work on the endorsement of the existing Web Accessibility Initiative (WAI) guidelines, making the design and content of all public websites accessible to disabled people. The question of web accessibility is important because of its increasing use. Easier accessibility to the web for disabled people also yields benefits for other users (e.g. the elderly).

The Council of Europe adopted a Resolution on Universal Design in 2001. It recommends the generalisation of certain national practices, incorporating universal design principles into the curricula of architects, engineers and town planners, and into the training of all vocations working on the built environment.

Universal design standards should be used to increase access to information and communication technologies. Certain initiatives aimed at adapting legislation and standards with universal design (as in Denmark and Sweden) should be assessed and spread to other Member States. The Danish

**Table 11 Provision of services (main measures)**

	<b>B</b>	<b>DK</b>	<b>D</b>	<b>EL</b>	<b>E</b>	<b>F</b>	<b>I</b>
<b>Measure</b>	Integration allowance.	Law on the provision of services for the disabled.	Federal social assistance Act.	Elderly persons in need of care.	Assistance of a third person.	Compensatory benefit for help of a third person.	Social insurance in case of disability (severe disability).
<b>Definition</b>	Inability to live independently and inability to function in everyday life.	Due to impairment or sickness has a special difficulty in managing ordinary operations of life on a long-term basis.	Considerably physically, mentally or psychologically disabled and affected adversely in their participation in social life.	Persons suffering from paraplegia / tetraplegia and absolute disability. Home help in certain communes.	As a consequence of anatomical or functional loss need help... to carry out the most essential acts of life ...	Persons requiring regular help of a third party in order to accomplish the basic daily tasks. Lack of autonomy in ordinary daily activities (APA).	Physical, mental or sensory conditions causing difficulties ... and leading to social exclusion. Need the help of a third party to move around or require assistance to carry out basic daily tasks.
<b>Assessment</b>	Use of ADL -related scales.	Activities of daily life but does not need constant institutional care. Drugs excluded.	Assistance in special life situations (participation, integration, care).	Medical: need of supervision, care and support provided by a third party.	Ability to live independently.	Medical, social & environmental factors.	Use of ICDH-2.
	<b>IRL</b>	<b>NL</b>	<b>A</b>	<b>P</b>	<b>FIN</b>	<b>SW</b>	<b>UK</b>
<b>Measure</b>	Constant attendance allowance.	Provisions for the handicapped Act.	General attendance allowance Act.	Supplement for dependency.	Law on the provision of services for disabled.	Handicap allowance.	Disability Living Allowance
<b>Definition</b>	Severely disabled who require another person to care for them.	Limitations in the field of living or moving in and outside the dwelling, due to sickness or infirmity.	Permanent need for support and care due to physical, mental, emotional or sensory disability.	Need of care for successfully carrying out the activities of daily life.	Due to impairment or sickness has a special difficulty in managing the ordinary operations of life.	Need help from another person for a) daily activities; b) gainful employment or c) has considerable extra costs.	Need of care from another person because of illness or disability (- 65 years old) Attendance allowance: need personal care due to physical or mental disability (65+)
<b>Assessment</b>	Medical.	Socio-medical assessment of need (mobility and housing).	Medical report (includes daily activities, mobility).	Assessment by the Service of certification for incapacity.	Independent living. According to needs prevalent in the municipality.	Medical diagnosis and need of care.	Ability to do activities of daily life

Source: Brunel – National Reports, 2002 ; MISSOC, 2001.

Ministry of Research has established a reference group to ensure that the needs of people with disabilities are taken into account in the formulation of initiatives that develop information technology.

Several Member States have taken initiatives to adopt web accessibility guidelines for public websites. For example, since the Law for Equal Opportunities for Persons with Disabilities was passed in Germany in May 2002, all government offices and services have to redesign their web pages in order to comply with accessibility standards. These include pronounced colour contrasts and large fonts.

### **Services**

In Ireland the Equal Status Act, 2000, prohibits types of discrimination in connection with the provision of services, property and other opportunities to which the public generally has access. Cases of complaint have concerned access to pubs, hotels and other buildings, and to insurance, banking and educational facilities.

In the United Kingdom, under the Act regulating the provision of goods, facilities and services, it has been unlawful since 1996 for service providers – shops, restaurants, banks etc. – to treat disabled people less favourably than other people for a reason related to their disability, for example by:

- refusing to provide a service;
- providing a lower standard of service;
- providing a service on worse terms.

From 1 October 1999 service providers have had to make reasonable adjustments to the way in which they provide goods, facilities or services. They are encouraged to plan for further obligations, which are due to come into force in 2004. These will require service providers to make reasonable adjustments to physical barriers to their services.

In the USA, Title III of the ADA specifically considers reasonable access to public places, such as restaurants, shopping centres, theatres and museums. A survey of retail business by C. Kaufman-Scarborough (1999) finds that, despite existing legislation, access remains incomplete. She believes that architectural interpretations of the Act do not create the reasonable access that mobility-disabled shoppers actually want. She advocates that reasonable access depends heavily on a commitment by individual retailers to interpret the Act in terms of consumer experience. She concludes that public policy ought to assist retailers in developing a code of reasonable access based on their own professional standards.

### **Buildings**

In the majority of Member States initiatives have been taken to improve the accessibility of public buildings and to adopt rules friendly to disabled people in new constructions. A prevention strategy, based on sensitising and informing architects during their training, is often adopted. Exceptions to universal access and design for all could only be granted to environments that are particularly vulnerable from a cultural, historic, environmental or artistic view.

Existing public buildings and other public places in Sweden must be made accessible to people with disabilities by 2010. Local authorities risk penalties if they fail to provide people with the support that the courts have found they are legally entitled to receive. Elements of a 'design for all' programme can be found in all Member States. Austria is going one step further by promoting a disabled-friendly environment. It will put into place measures on disabled-friendly furnishings, job design and technical installations in work places.

Another important policy followed by the Member States concerns the accessibility of transport and communication services. An increasing number of Member States follow a policy of accessible transport services mainly by the acquisition of new public transport vehicles. The most ambitious programme has been initiated by the Netherlands. It aims to make rail and regional bus transport fully accessible in 2010 and 2030 respectively. Accessibility measures relate to rolling stock, stations, platforms, bus stops, timetables, automatic ticket offices, etc. When the government awards a public transport contract, it must include accessibility as part of its requirements.

Public procurement could be a tool for including a disability perspective at the level of conception. It ought to ensure that people with disabilities can make use of the same goods and services as other members of society. Accessibility and functionality could be among the selection criteria. Grants for housing adaptation are made widely available in the Member States.

### **Leisure**

Measures to promote the access of disabled people to leisure, tourism and cultural activities have been adopted in some countries, notably in Ireland and Denmark.

An important element in Danish cultural policy is to ensure that people with disabilities have the same access to cultural life as everybody else, both as active performers and as audience. In March 1997 the Ministry of Culture published a 'Report on Access of People with Disabilities to Cultural Activities', which includes a number of recommendations within an action plan. One element of this plan is to ensure that buildings that accommodate cultural activities are accessible to people with disabilities. The plan also contains 'information initiatives' to make it easier for people with disabilities to take part in cultural activities.

The Office of the Disability Ombudsman in Sweden has suggested that government grants to cultural activities should be made conditional on the requirement that they take place in premises that meet accessibility standards.

### **Participation of people with disabilities in the design of policies to eliminate physical barriers**

In France a liaison committee on transport for people with a disability is consulted on any development in public transport. It brings together civil servants, public bodies and associations.

In the Netherlands the Inter-ministerial Committee has set up a permanent committee on accessibility: the Central Coordination Point for the Promotion of Accessibility. In this framework consultations are held with the 'private initiative': the Netherlands Disability Forum. In Finland the Council on Public Transport is attached to the Ministry of Transport. Several ministries, the Finnish

Federation of Municipalities, organisations of people with disabilities and different transport suppliers are represented on this council.

In the United Kingdom the Disabled Persons Transport Advisory Committee advises the Secretary of State for Transport on issues affecting the transport and mobility needs of disabled people. The committee has 20 members, the majority of whom are required by statute to be disabled. The Committee has been particularly active in producing technical specifications for the accessibility of means of transport that are widely adopted by the transport industry.

Disabled people's organisations complain that they are generally brought into the process too late, when the decisions have in practice already been taken. Participation and dialogue at the local level is important since people with disabilities know their problems and needs better than anybody else. Their experience has equipped them with some expertise. So it is important for municipalities to give local disabled people's organisations better opportunities to comment on plans, new building projects and adaptations to existing ones. This would help to prevent many mistakes.

Norms and standards will only be respected if they are accompanied by sanctions. These sanctions could consist of refusing public funds, imposing an obligation on the offender to redress the situation and bear the cost, etc.

## Public expenditure

During the 1990s EU Member States adopted restrictive policies that led to sharp relative decreases in disability-related expenditure. In 1999 the representative expenditure on disability-related programmes accounted for 2.28% of GDP. The average percentage was 2.7%, but this is not representative as the share in the Netherlands and Sweden was much higher than in other Member States. Member States with very high rates like Denmark, the Netherlands and Sweden have pursued restrictive policies that have led to significant relative decreases. OECD (2002) notes that the decrease reflects two factors:

- a levelling effect: a stabilisation or decline in the inflow of new beneficiaries;
- a composition effect: among new demands, the share of non-contributory benefits has increased at the expense of contributory pensions in countries with a dual system (e.g. Italy and Belgium); or non-contributory benefits are means-tested and lower compared with earnings-related pensions.

**Table 12 Public expenditure on chronic illness and disability**

	Disability benefits (broad definition)			All disability-related programmes	Employment-related programmes	
	1990	1999	Relative change			1999
	% of GDP	%				% of GDP
B	2.21	1.61	-27	1.72	0.11	
DK	3.70	3.31	-11	3.78	0.47	
D	3.22	2.90	-10	3.08	0.18	
E	2.11	2.26	7	2.28	0.02	
F	1.70	1.58	-7	1.67	0.09	
I	2.25	1.82	-19	1.83	0.01	
NL	5.74	4.14	-28	4.64	0.50	
A	2.62	2.85	9	2.92	0.07	
P	1.89	1.48	-22	1.53	0.05	
SW	5.21	4.02	-23	4.66	0.64	
UK	1.39	1.52	9	1.54	0.02	
<b>Average</b>	<b>2.91</b>	<b>2.50</b>	<b>-11.00</b>	<b>2.70</b>	<b>0.20</b>	
<b>Median</b>	<b>2.25</b>	<b>2.26</b>	<b>-10.54</b>	<b>2.28</b>	<b>0.09</b>	
USA	1.48	1.37	-7	1.40	0.03	

Source: OECD, 2002. Administrative data.

Disability benefits: contributory (earnings related) and non-contributory disability benefits.  
 Broad disability benefits: disability benefits, sickness cash benefits and work injury benefits.  
 All disability programmes: broad disability benefits and employment-related programmes for disabled people.  
 Sickness cash benefits: in most countries this group is rather small because a large proportion of shorter-term sickness absence – the period of continued wage payment by the employer – is not included.  
 Average and median: Non-weighted.

Spending on employment-related programmes for people with disabilities is more difficult to interpret. A preference for mainstreaming programmes and the absence of relevant data may result in a reduction in expenditure. Normally expenses related to people with disabilities should be



included in ordinary programmes. Consequently, the data in the table presents mainly expenditure on specific programmes.

### Disability pensions

This section does not aim to be an exhaustive presentation of national policies on disability pensions in the Member States. It does aim to identify the main trends in the criteria for the granting of disability pensions.

The focus is on mainstream schemes. In countries where there is a contributory and a non-contributory scheme, preference to the contributory one is given (e.g. Belgium, Ireland and the United Kingdom). For comparison it should be noted that non-contributory schemes are generally part of social action to combat poverty and are consequently means tested. Also, non-contributory schemes require more stringent conditions (for example, higher levels of disability degrees in Greece, Ireland and the United Kingdom) than social security schemes. Finally, many countries have different schemes according to the sector of activity (public/private, agriculture/industry, etc.). For these countries, the table following presents private, employees' schemes.

Chronic illness and impairments are the most common criteria defining the coverage of the schemes. In general, the term 'physical impairment' includes chronic diseases. A major difference arises over 'mental' problems, notably psychological impairments (emotional, behavioural, etc.). Since the 1990s a majority of countries have included mental health among the conditions giving a right to a disability pension. However, the increasing number of people with mental problems and the difficulty of assessing them has led many countries to be cautious in the treatment of such cases.

Reduced work capacity tends to be generalised as another common criterion. Terms like 'earnings capacity', 'reduced ability' or 'loss of wage' often refer to broadly the same method of assessment. By contrast long-term care dependency, as was noted in the previous chapter, refers to care needs and a different method of assessment.

The assessment of the work reduction is mainly medical (impairment). In most cases reference is made to 'suitable' or 'appropriate' work, which means that social factors such as education and experience should be taken into account. However, this is not always so in practice. Large discrepancies may arise if the required minimum degrees of disability are compared. Moreover, the minimum period for an illness or disability to be considered permanent ranges from six months to one year. However, in some cases it could be three years (Portugal).

A number of elements could constitute the basis for European harmonisation. This could cover social security schemes and include:

- a list of impairments, as defined by ICDH;
- a set of social factors (age, education, experience, etc.);
- a range of minimum requirements for the degree of disability (for example: a work reduction of 30% for basic disability pensions);

**Table 13 Disability pensions and allowances (social security and social assistance: main measures)<sup>12</sup>**

	B	DK	D	EL	E	F	I
<b>Measure</b>	Work incapacity benefit/invalidity.	Law on active social policy.	Incapacity pension.	Incapacity pension (Social Insurance Institute).	Law on Social integration of disabled.	Social security invalidity.	Ordinary invalidity grant.
<b>Definition</b>	Injuries or functional impairments that limit his/her earning capacity to 1/3 or less of what a non-disabled of the same social class and with the same level of education could earn in the same or similar occupation.	The Social Ministry defines working ability as 'the ability to fulfil the demands that are put on the labour market to do different, specified tasks in order to gain an income. Reduced ability could result from illness, disability, long-term unemployment ...'.	Reduced capacity to earn a living. If due to illness or disability (including mental) work capacity is reduced.	Due to disease, impairment, physical or mental reduction he cannot earn, from work corresponding to his skills and education, more than 50% of usual earnings (partially invalid).	Those with reduced chances of educational, work-related or social integration due to a permanent impairment, congenital or other, of their physical, mental or sensorial abilities.	Physical or mental impairment that reduces the working capacity or the wage opportunities.	Person whose working capability has been permanently reduced.
<b>Assessment</b>	Chances of a successful return to work. Medical doctors. Questions if mental problems but not illness.	Need of provision. Working ability. Reduced ability could result from long-term unemployment	Capacity to work. 'Rehabilitation before pension.' Medical but takes into account workplace adaptation. Use of ICD.	Earnings capacity. Medical and occupational factors.	Medical & social. Use of ICDH and ADL. Drugs. Multidisciplinary. Minimum guaranteed income refers to: unable to obtain appropriate work.	Work ability, age, professional environment.	Medical assessment, restrictions in activities of daily life, ability to undertake employment and social activities.
<b>Measure</b>	IRL Disability allowance.	NL Disablement benefit Act.	A Disability pension (employees).	P Invalidity pension.	FIN Law on National Pension.	SW Early retirement Social Security Act	UK Incapacity benefit.
<b>Definition</b>	Injury, disease, illness, physical or mental disability making him/her substantially handicapped for work considered suitable, given experience and qualification.	Due to sickness or impairment, cannot earn with labour what non-disabled, with comparable education and work experience, usually earn	Inability to earn, due to physical, emotional or mental condition, half the amount of a healthy person with similar education and skills	Loss of wage due to physical or mental capacity for work.	Due to sickness, impairment or injury, unable to perform his/her usual work ... which must be considered appropriate and secure reasonable income taking into account age, qualifications ...	Reduced work capacity due to physical, mental or other medical reasons.	Due to disease, bodily or mental disablement, incapable of doing work that could reasonably be expected to do in a) previous occupation or b) all work.
<b>Assessment</b>	Ordinary activities of life and work. Mainly medical.	Medical capacity profile and earning capacity assessed by the use of a function information system.	(Mainly) medical & labour market. There is no degree of disability. 'Rehabilitation before pension'.	Medical & vocational. National list of incapacities	Earnings are used as an indicator of working capacity. Use of ICD. Multidisciplinary.	Mainly objective medical reasons.	a) Own occupation test. b) Capability test: extent to which he/she is able to carry out activities relevant to work. Test on 14 activities. Medical.

Source: Brunel – National Reports, 2002; MISSOC, 2001.

<sup>12</sup> Minimum duration (in general six months to one year) and degree of disability (in general between 33% and 50% minimum) are not reported here.

- the definition of a minimum period for a permanent illness or disability (but periodically revisable, if necessary).

The definition of minimum standards at EU level could consist of a general minimum framework. Member States should be free to choose the appropriate way to achieve them.

### Policies to reduce the number of beneficiaries

The decrease in relative expenditures has been in some cases accompanied by a decrease in the number of beneficiaries (e.g. Finland), but in general the number of beneficiaries has been stable or slightly increased. The reduction in new entries mainly reflects restrictive policies. For example, in Finland stricter medical conditions have been applied since 1998.

**Table 14 Recipients of disability/anticipatory pension by sex**

		Denmark		Finland		Sweden	
		M	F	M	F	M	F
1990	Recipients	76,113	78,481	159,509	141,423	166,716	188,600
	New accession	6,638	5,597	...	...	23,643	26,850
	New accession as % of population	0.4	0.3	...	...	0.9	1.0
1999	Recipients	81,903	83,721	149,944	132,095	186,461	238,489
	New accession	3,672	3,274	...	...	17,587	21,919
	New accession as % of population	0.2	0.2	...	...	0.7	0.9

Source: NOSOSCO, 2001.

The Netherlands and the United Kingdom are exceptions. The table following shows that the disability benefit inflow rate represents about 6% of the working-age population in most European countries, except the Netherlands and the United Kingdom where it represents more than 10%.

Total expenditure in the Netherlands on illness and disability as well as the total number of disabled people is significantly higher than in other European countries. It has been argued that until the late 1980s, the disability programme was administered by employer and employee organisations and both parties had an incentive to divert superfluous workers into the disability programme (H. Buddelmeyer, 2001). This programme had a more generous benefit structure than the regular unemployment programme. H. Buddelmeyer considers that the disability programme was not only (mis)used as a place to dump redundant workers, but it also provided an incentive for employees to retire, especially when these employees approached retirement age. It was estimated that by the end of the '80s about 10% of the observed inflow into disability were in fact dismissals (Hassink et al, cited in H. Buddelmeyer, 2001).

Similar practices are found in Germany, notably in the case of businesses undergoing substantial reductions in their workforces (R. T. Riphahn, 1997). These problems led many countries to revise their disability accession schemes, particularly by imposing stricter conditions, as in Germany in the mid 1980s and the Netherlands in the late 1980s.

Before 1987 the Netherlands disability assessment process asked for labour market conditions to be taken into account, that is to say the probability of finding commensurate employment. This was abandoned in 1987. In 1993 the notion of commensurate employment was also modified. It was no longer defined by educational attainment, work history or vocation, but instead applied to all work that disabled workers were still able to do, given their experience, education and physical and/or mental limitations. Also, in computing their remaining earning capacity, comparison was made with jobs available at a national level and not only at a regional level (H. Buddelmeyer, 2001).

## Early retirement and elderly disabled people

The number of people receiving a disability pension increases with age, notably for those aged 50 plus. The following table shows that more than 60% of all disability pensioners in the Nordic countries are older people (between 50 and 65 years old). Also, disability reciprocity rates increase significantly with age. The pattern is similar to that of self-reported disability.

The disability benefit inflow rate is higher in the 55-59 age group than in the 60-64 age group (for example in Germany, Denmark, Austria (men) and the United Kingdom (men)). This indicates that potential claimants could benefit from early retirement measures. In fact in many countries the long-term unemployed and the unemployed with disabilities, aged 60 (or under) to 64, may receive early retirement pensions (e.g. Austria, Belgium, Finland and Ireland). Furthermore, in certain countries the retirement age is less than 65, notably for women (for example in France, Austria, Italy and the UK). Consequently, comparisons involving people aged 60 to 65 are difficult to make.

**Table 15 Pensioners receiving disability/anticipatory pensions**

	Denmark			Finland			Sweden		
		%	% same age		%	% same age		%	% same age
16/18-19	,564	0.4	0.2	1,906	0.7	0.7	3,567	0.8	0.9
20-29	7,501	4.9	1.0	8,216	2.9	1.3	13,118	3.1	1.2
30-39	18,267	12.0	2.2	18,564	6.6	2.5	32,668	7.7	2.6
40-49	33,107	21.7	4.5	44,440	15.8	5.6	75,830	17.8	6.5
50-59	59,743	39.2	8.1	105,150	37.3	14.8	167,218	39.4	13.9
60-64/66	33,352	21.9	12.8	103,763	36.8	39.4	132,549	31.2	30.8
<b>Total 18-64</b>	<b>152,534</b>	<b>100.0</b>	<b>4.3</b>	<b>282,039</b>	<b>100.0</b>	<b>8.3</b>	<b>424,950</b>	<b>100.0</b>	<b>7.7</b>
65-66	12,259		13.5						

Source: NOSOSCO, 2001. Administrative data.

**Table 16 Disability benefit inflow rates, 1999**  
Inflows per 1000

Age	DK	D	E	I	NL	A	P	SW	UK
55-59	10.4	16.5	7.9	1.4	9.9	28.4	16.5	16.4	20.5
60-64	8.4	13.7	7.9	1.4	9.3	4.1	21.8	21.7	10.6

Source: OECD, 2002. Administrative data.

Lindeboom et al (2002) exploit longitudinal data for the early 1990s and find that financial incentives in the Netherlands were important determinants of the retirement decision. Workers in the Netherlands had strong incentives to take an early retirement scheme provided by an employer as soon as they were eligible for it. They note that eligibility for an early retirement scheme substantially reduced the probability of early outflow through disability insurance and unemployment insurance schemes. The Dutch reform modified this situation.

When comparing the disability inflow rates for a given age there is a large variation between countries. Given the fact that reported illness and disability does not vary very greatly across countries, one hypothesis could be that the variations are the result of the differences in social security and social protection schemes available in the Member States. This has increased pressure for reforms, notably towards restricting social security and public pensions.

### Replacement rates

High benefits are thought to act as a disincentive to work and an active search for work. So considerable research has been devoted to estimating the effects of higher benefits on the number of disability beneficiaries, and thus on participation in work.

One measure often used is the 'replacement ratio', that is the ratio of expected disability benefits to net average wage earnings. One robust result from different studies seems to be that rising benefit levels have a significantly positive effect on the disability inflow rates and hence the number of beneficiaries. However, there is a considerable debate on the magnitude of this effect.

The figures below (22 and 23) indicate that there is a strong collinearity between net replacement rates and self-reported illness and disability for elderly workers between countries. Countries with high net replacement rates tend to have more (self-assessed) people with illness or disability. If it is accepted that self-reported disability is a good proxy for the number of potential disability claimants, then the graph suggests that countries with high replacement rates tend to be characterised by high numbers of disability beneficiaries.

For the replacement rate the OECD global rate including unemployment benefits and social benefits is used (J. P. Martin, 2000). In order to be as close as possible to people aged 55 to 59, the case is that of a married couple without children. In order to take into account reduced work capacity the case is that of a person able to earn 66.7% of the average salary of a production worker. In many countries the financial situation of the unemployed and those relying on disability benefits is very similar, although disability benefit could be slightly higher in some countries. The differences between the two replacement rates are negligible, notably between social security schemes for employees and unemployment schemes. This is due to the fact that length of service and the final wage play a dominant role in the calculation of both disability and unemployment benefits<sup>13</sup>.

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<sup>13</sup> Only social assistance schemes provide, in general, flat rates.

A relatively small number of studies have been devoted to estimating the effects of higher benefits on the number of disability beneficiaries in Europe. Riphahn finds that a 10% cut in benefits in Germany leads to a decline in the probability of transition to disability retirement of about 4% for elderly workers. So the impact on exit from working into disability retirement is small. By contrast, wage changes have a much stronger effect (R. T. Riphahn, 1999). British studies have also found that expected benefits have a positive impact on the probability of invalidity retirement. In Norway, however, the replacement rate is not significant (E. Bowitz, 1997).

In general, blue-collar workers and poorly educated people are expected to enter disability retirement in higher numbers. Their net replacement ratio is higher compared with other groups. In the late 1980s about 32% of all male blue-collar workers in Germany were entering disability retirement before reaching the age of 60 (R. T. Riphahn, 1999).

H. Buddelmeyer finds that a reduction in benefits of 25% leads to a reduction of 2% in the mean wage expected. By contrast, an increase in the benefit level of 25% leads to a 9% increase in the mean wage expected. He concludes that reducing benefits as a measure to increase the incidence of people returning to work is not very effective since the probability of their accepting a job is already very high. Policies designed to increase the number of people returning to work should therefore aim to increase the probability of obtaining an offer, rather than look to increase the probability of acceptance.

In the USA the decline in male participation in work, accompanied by a parallel rise in male disability benefit receipt, has generated an extensive literature. The reported estimates are generally higher compared with European countries, but there is strong disagreement on the extent of the difference. Most studies report that a 10% reduction in disability benefits leads to a reduction of 3% to 10% of (male) applications. For example, Riphahn (1997) estimates that the simulated response to a 10% benefit cut is a 10% reduction in male applications. Simulations indicate that women respond with only a 2% decline in applications to the same benefit reduction. This result suggests that women's decisions on whether to apply for disability benefits tend not to be substantially motivated by the monetary rewards. The results are for people aged 50 to 61.

These results have been challenged by studies that find health is one of the strongest predictors of disability retirement. Riphahn (1999) finds that the magnitude of the health effect<sup>14</sup> exceeds that of the benefit variable by far, and that a strong health effect has been found in all studies of German retirement behaviour. Furthermore, these estimates are fairly insensitive to the particular measure of health. She notes, moreover, that foreign workers are less likely than native Germans to retire due to disability, but may be more likely to enter non-employment (including unemployment).

There is also much evidence that poor health has a larger effect on labour force participation than any other individual variable, and that rejected applicants for social security disability benefit are unlikely to work (S. Stern, 1996; J. Bound, 1989). Furthermore, controlling for current health is associated with continued participation. It appears that not just poor health, but declines in health, explain retirement behaviour (J. Bound, 1998).

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<sup>14</sup> Salkever et al, 1997, find that the effect of health variables is not significant.

J. Bound (1989) notes that regression techniques comparing the labour force participation rates of those with high replacement rates to those with low replacement rates are likely to overestimate the impact of disability benefit on participation in work. In fact, it is difficult to determine whether it is generous replacement rates or low earnings that induce individuals to leave the labour force. He stresses that there are a variety of reasons for expecting that those with low earnings would be the ones most likely to leave the labour force regardless of disability benefits. The coefficient of the replacement ratio is picking up these other effects and so exaggerating the causal impact of the disability benefit itself.

Bound studies the rejected pool of applicants. The assumption is that rejected applicants were healthier and more capable of work than those who were accepted. So their performance at work should provide an upper limit for what could be expected of disability beneficiaries. He finds that in the US fewer than 50% of rejected male applicants work. Furthermore, the earnings of those who do return to work are roughly 30% below pre-disability levels and more than 50% below those for other men of comparable age. Also, a surprisingly high proportion of rejected candidates in Finland seem to have health problems (T. Hakola and M. Lindeboom, 2001).

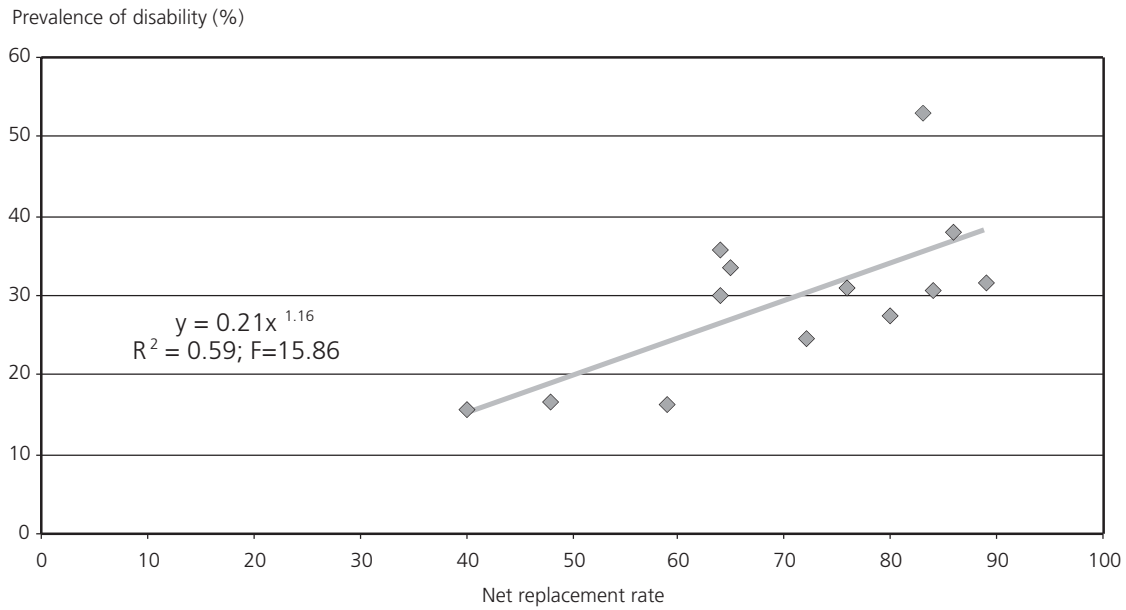
In the European Union about 50% of inactive people with severe illnesses or disabilities say that they are not seeking a job because of illness, injury or incapacity (men: 57.5%, women: 45.8%). For those with a moderate disability the corresponding rates are 31% for men and 17.3% for women (Eurostat, 2001). These data cast doubt on recent studies suggesting that the disincentive effect of disability benefits have been substantial.

One important question is whether policies ought to focus on people with disabilities or on employers. Some studies draw a distinction between demand and supply effects. Demand effects refer notably to (expected) wages offered by employers. People with disabilities have lower expected wages because employers could consider that they are limited in the kind of tasks they can perform. This plays against participation in the labour market. Supply factors refer notably to 'reservation wages', technical aids and environmental factors. Disability benefits tend to increase the reservation wage – that is the minimum wage required by someone in order to accept a job offer. A hostile environment may further limit the type of work a disabled person can do. Both factors discourage people with a chronic illness or disability to be economically active.

The magnitude of each factor is under debate. There is, however, an increasing consensus that efforts to improve the accessibility of public transport, the adaptation of workplaces and home care services are likely to be more successful than wage subsidies. The studies discussed above indicate that benefit incentives have a small effect on the labour participation of people with an illness or disability. So a policy focussing on reductions in disability benefit is likely to fail. This probably explains why countries wanting to reduce disability applications focus on eligibility criteria, notably by applying more stringent conditions or stressing medical criteria.

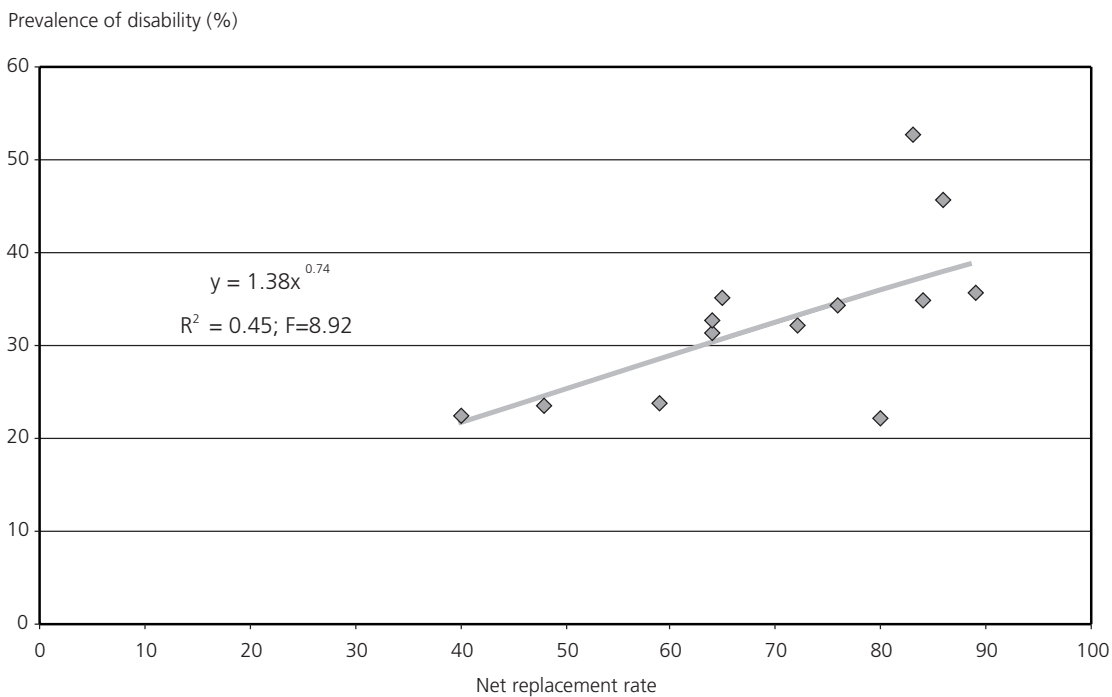
It is important to note that reducing the effect of chronic illness and disability on disabled people will not make them the same as the average non-disabled person. Even if the supply and demand effects of disability are totally erased, the probability of participation will not reach the average for non-disabled people. This is because people with an illness or disability are more likely to be older and have less education than the non-disabled, which makes them less likely to work (S. Stern, 1996).

**Figure 22 Prevalence of disability (age 55-59) and net replacement rate (13 countries)**



Source: Eurostat, 2001 and OECD, 2002.

**Figure 23 Prevalence of disability (age 60-64) and net replacement rate (13 countries)**



Note: For the net replacement rate the OECD global rate including unemployment and social benefits is used (see discussion in the text). If the estimate has no constant, both elasticities are close to 0.8.

Source: Eurostat, 2001 and OECD, 2002.



## Unemployment and disability benefits

Some have advanced the argument that increasing unemployment results in higher incidence of disability benefit and/or exit from the labour market. In other words disability retirement is over-used by individuals who are unemployed but not really disabled. This assumes that both groups, the unemployed and disability beneficiaries, share the same characteristics. The argument continues that, given the fact that in general disability benefits are more generous than unemployment benefits, public policy ought to be more restrictive in granting disability pensions. It is of course not fair to assume that both groups share the same characteristics. However, this could be true for people with a moderate disability and people who are long-term unemployed. In fact, in some countries those with an illness or disability are treated as part of a larger group of people with reduced ability. This group includes the long-term unemployed who face difficulties integrating into the labour market (Denmark).

A positive association between application for disability benefit and unemployment benefit was found in the following countries:

- Germany, by Riphahn (Riphahn, 1997);
- Germany and the Netherlands, by Aarts and de Jong (cited in Riphahn, 1997);
- Norway, by Bowitz (Bowitz, 1997);
- the USA, by Kreider (cited in Riphahn, 1997).

De Mooij estimated that as much as 50% of disability benefits in the Netherlands were due to improper use (cited in H. Buddelmeyer, 2001). Also E. Westerhout found that about half the participation in disability schemes could be characterised as hidden unemployment. A quick calculation shows that if disability inflow rate (not the stock of beneficiaries) is reduced by half the figure arrived at is about 6%, which is the average for European countries.

Finnish data support the hypothesis that there is some interchangeability between unemployment and disability (Hakola, 2000). In fact the probability of moving from employment to unemployment decreases when there is a health problem. In other words the presence of a health problem pushes the individual to go directly into retirement rather than to move to unemployment. By contrast, German data indicate that there is little correlation between aggregate unemployment and individual disability retirement (Riphahn, 1997). There are some factors – for example wages – with very similar effects on both disability retirement and unemployment, but other factors do have distinct effects.

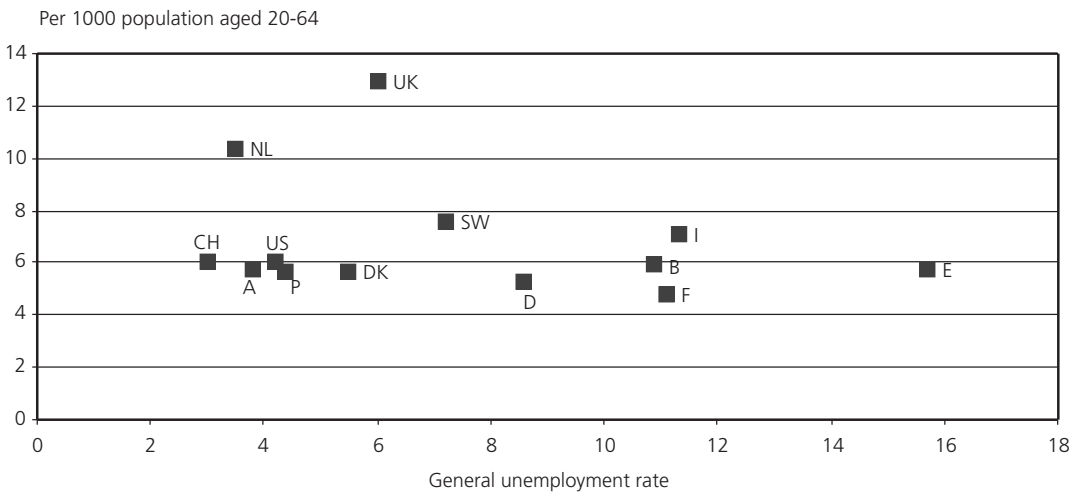
Figures 24 and 25 show that the unemployment rate has no impact on the disability inflow rate in the EU. The disability inflow rate is about 6% for most European countries, independently of the unemployment rate. Only the United Kingdom and the Netherlands significantly diverge from the European average.

Figure 26, on the severely disabled, indicates a negative correlation between disability prevalence and the unemployment rate by age group. For young people the attraction of work is high compared with potential disability benefits. Young job-seekers have a distant horizon ahead of

them, with an anticipated growth in potential work earnings. So they will have a strong disincentive to identify themselves with illness or disability and to apply for disability benefits, implying an exit from the labour market. For younger age groups with poor health or a disability, unemployment is preferable to disability status (and inactivity). Stigmatisation could also be an important disincentive as it reduces expected future earnings from work.

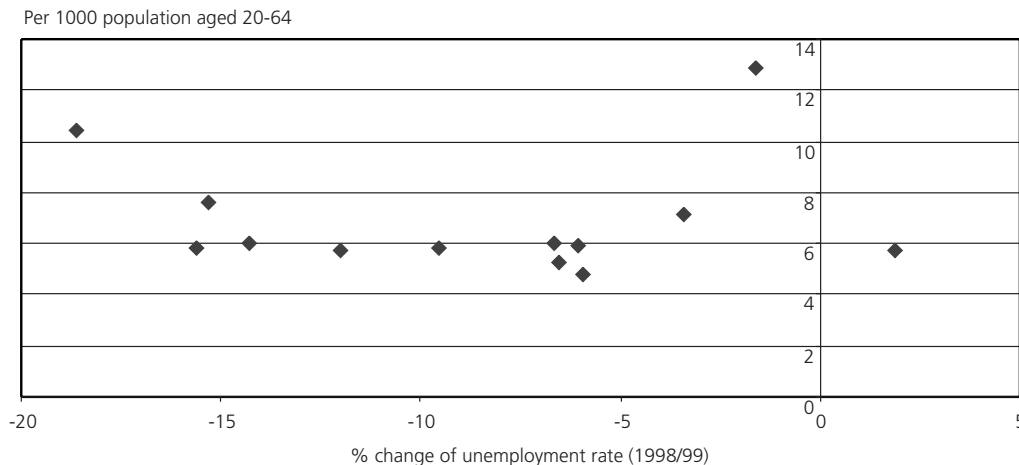
By contrast unemployed, older workers with poor health or a disability have little chance of finding a job and even less chance of increasing their work earnings in the years following. Furthermore, the amount of a disability benefit depends on past wages and seniority. So they could be more inclined to identify themselves with illness and disability and apply for disability benefit, implying an exit from the labour market, especially if their health is deteriorating. As a result, the figure reflects a certain degree of interchangeability between unemployment and inactivity for older people with severe disabilities.

**Figure 24 Disability benefit inflow rate and general unemployment rate (1999)**



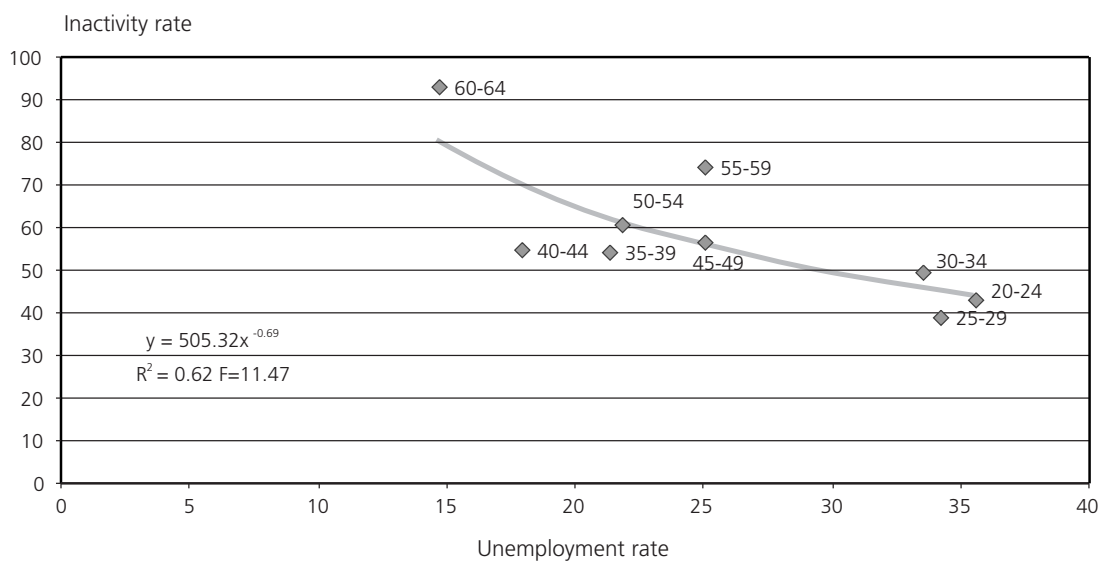
Source: OECD, 2002

**Figure 25 Disability benefit inflow rate (1999) and unemployment change**



Source: OECD, 2002.

Figure 26 Inactivity and unemployment of the severely disabled, by age group, EU 1996



Sources: Eurostat, 2001. Survey data.

## Definition of the target group

This chapter presents a comparative analysis of measures to integrate people with disabilities into the labour market:

- measures relating to the open labour market;
- personal support and workplace adaptations;
- the quota system; and
- sheltered employment.

It is important to note that these measures focus on people who satisfy a certain number of conditions. This enables policy-makers to focus on a group with particularly significant problems of integration into the labour market. The next table (17) presents the characteristics of these beneficiaries. The only exception is sheltered employment, which benefits those with an illness or disability and who cannot integrate into the ordinary labour market.

This does not mean that only beneficiaries of these measures make up the group of people with disabilities at work. Many with illnesses or disabilities do not receive a disability-related benefit or are not registered as disabled. In evaluating policies one ought to include all these people. The dominant criterion for the granting of an employment subsidy or assistance is the presence of difficulties in obtaining or keeping a job due to mental, physical or sensorial impairments. The definition, or a similar one, proposed by the International Labour Office (ILO) in its Convention N° 159, is used in certain countries (Portugal, Finland, and Belgium, France and Sweden).

As regards the nature of an illness or disability, physical, intellectual and psychological limitations are taken explicitly into account by the majority of Member States. Furthermore, drug addiction is explicitly included in some countries (for example, Germany and Ireland). In comparison with social security benefits, the present definition of beneficiaries is broader. Employment and other social criteria are more often used in the assessment process. The desire to compensate for a disadvantage and to ensure equal opportunities appears to be the main orientation of national policies.

## Integration into the open labour market

The European Union has played an important role in the development of training and employment policies in favour of the disabled. The 'HELIOS' programme, the 'Employment Initiative' and currently 'EQUAL' have promoted training and employment creation for people with disabilities. The extensive exchange of good practices across the Member States has led to a certain harmonisation of policies.

The tables following (18 and 19) indicate that there is a large similarity between Member States in the measures adopted. The main ones include:

- labour subsidies, granted either to the employee (increase in wage income) or the employer (reduction in labour costs);

**Table 17 Definitions of illness and disability for employment measures**

Law / Measure	B	DK	D	EL	E	F	I
<b>Definition</b>	Employment provisions (Flemish Fund). Long-lasting and substantial limitation of the possibilities of social integration due to reduced intellectual, psychological, physical or sensory capacities.	Law on compensation in employment. Preference (for public jobs) for persons who, because of disability, have difficulties in getting employment on the ordinary labour market.	Employment promoting benefits. Physical, mental or psychological difference and affected adversely in participation in social life Severely: if degree $\geq 50$ Equal status: if degree 30-50 and if they are not able to take up or keep a job.	Law N° 2643/1998. Limited capacities for professional occupation due to physical, intellectual or psychological disease or injury (disability rate $\geq 50\%$ ).	Law on social integration of the disabled. Reduced chances of educational, work-related or social integration due to a permanent impairment, congenital or other, of their physical, mental or sensorial abilities.	COTOREP. Possibility to obtain or keep a job is reduced by a loss or an insufficient physical or mental capacity.	Provisions in favour of handicapped. Physical, mental or sensory handicap causing difficulties in learning, in social relations, in integrating into labour market and that may lead to social exclusion or disadvantage.
<b>Assessment</b>	Reduced capacities hamper labour integration. Multidisciplinary.	Benefits only to persons with physical disabilities.	Work capacity (comparison with last or similar job)	Medical and occupational.	Medical & social. Use of ICDH and ADL. Multidisciplinary.	Medical and social.	Residual working capability. Global assessment of capabilities. Use of ICDH.
<b>Note</b>	If reduced productivity, right to a wage subsidy.	The law is rarely used.	Learning difficulties and addiction are included.	Employment subsidies also, requires a rate $\geq 50\%$ .	Drug addiction is included.		
<b>Law</b>	IRL Employment Equality Act.	NL Work handicapped (re) integration Act.	A Disabled persons employment Act.	P Regime for assistance in vocational training.	FIN Regulation concerning employment service.	SW Law on special measures for persons with work-related disabilities.	UK Access to work.
<b>Definition</b>	Bodily & mental impairments. Chronic disease or illness. Disfigurement, different learning & behaviour. Previous but no longer exists, or is imputed to the person.	Work handicap.	Functional impairment caused by an abnormal physical, mental or psychological state.	Difficulty in securing, retaining and advancing in a job, suitable to age, ability and professional experience, due to physical or mental impairment.	Prospects of securing, retaining and advancing in employment are substantially reduced as a result of a duly recognised physical or mental impairment.	Person who due to functional limitation has reduced work capacity and difficulties in gaining or keeping regular employment.	Physical or mental impairment which has a substantial and long-term adverse effect on his/her ability to carry out normal day-to-day activities, but only if disability affects work.
<b>Assessment</b>	Case by case. The definition is broad.	Medical capacity profile and earning capacity assessed by the use of FIS.	Medical criteria. List of impairments with corresponding disability degrees.	Medical & vocational. National incapacity table.	Health problems and employment prospects. Use of ICD. Multi-disciplinary.	Functional or work test. List of handicap categories.	Self-assessment and detailed interview with the person.
<b>Note</b>	Includes drug addiction and alcoholism.	Overlap with Act on disablement benefit.	Registration if degree $\geq 50\%$ : e.g. quota beneficiaries.	ILO. Quota: requires a severe limiting capacity.	ILO definition.	Definition used for all employment measures.	DDA definition.

Source: Brunel – National reports, 2002; MISSOC, 2001.

- special schemes to provide work experience; and
- start-up grants to set up own business and self-employment.

Efforts should not only be made by the people with a chronic illness or disability. Employers should eliminate barriers that impede their access to a job. So many countries have taken steps to promote the adaptation of the work place, through grants for work adaptation, (including physical, architectural and ergonomic adaptations) and the provision of technical aids (Table 19).

The provision of personalised support is important in most Member States. It includes grants for a tutor, job coach or a personal assistant in the enterprise, as well as support for groups of people. Some elements for an evaluation of these measures are given below. Austria goes one step further than 'design for all', by promoting a disabled-friendly environment. Austria will also put into place measures relating to disabled-friendly furnishings, job-design and technical installations in work places.

Telework and self-employment constitute an opportunity for people with mobility problems. They also have advantages for those who need permanent health care. But these jobs present the following problems:

- absence of social contacts,
- absence of any prospect of promotion, and
- instability.

In addition, social insurance schemes for independent workers are very disadvantaged compared with employee schemes, notably for health-related costs, disability benefits and unemployment allowances. So it is questionable whether these jobs are of any value for people with disabilities. One exception to this conclusion could be the creation of an enterprise, as this could generate much higher income to offset the disadvantages outlined.

Analysis of the National Action Plans against Poverty and Social Exclusion (European Commission, 2001) outlines the following measures aimed at eliminating these financial disincentives and promoting participation in the labour market:

- Sweden introduced a new 'activity allowance' for people under 30, to encourage them to undertake activities according to their ability without risk to their financial security.
- Finland allows disability pensions to remain dormant during periods of employment to help people with disabilities enter the labour market.
- Austria permits vocational integration subsidies with a temporary payment of wages as an incentive to recruit young people with disabilities; invalidity pensions will be accompanied by measures to prevent the drift into social exclusion.

In the United Kingdom, the government has modified the social security rules for disabled people on long-term incapacity benefits. The purpose of the reform was to make it easier for them to take up employment by guaranteeing that if their job does not work out because of their illness or disability, they will be able to return to their previous level of benefit up to a year later.

In April 1999 further changes were made to the benefit rules to help people with disabilities back to work. They include allowing those on incapacity benefits to earn a small amount of money and to take trial periods in jobs without losing the benefit. Accumulating income from work while drawing a social security invalidity pension is also allowed in Belgium. Wage subsidies are offered extensively in the new candidate countries but in many they are not used.

**Table 18 Employment measures for people with disabilities (main national measures)**

<b>B</b>	<b>DK</b>	<b>D</b>	<b>EL</b>	<b>E</b>
Wage cost subsidies (i.e. permanent wage subsidies, grants to employers to compensate reduced productivity).	Labour-cost subsidies (i.e. permanent wage subsidies to compensate lower productivity).	Wage subsidies. Compensatory assistance to severely disabled. On-the-job-support: individual job coach.	Employment subsidy.	Open ended contracts. Short-term contracts. Training contracts.
Grants for self-employment.	Grants to employers for the salary of a personal assistant.	Measures to foster initial placement.	Grant to set-up own business.	Measures for self-employment.
<b>F</b>	<b>IRL</b>	<b>I</b>	<b>L</b>	<b>NL</b>
Labour-cost subsidies (i.e. permanent). Personalised assistance in job search. 5-year convention for long-term unemployed and young disabled.  Assistance for starting enterprises.	Wage subsidy.	Total or partial annual relief for firms. Special hiring for the psychically disabled.  Starters' credit. Targeted placement. Conventions with disabled freelance workers.	Job subsidies.	Wage dispensation. Trial appointment. Supplement to salary. Supplement to income. Appointment budget.
<b>A</b>	<b>P</b>	<b>FIN</b>	<b>SW</b>	<b>UK</b>
Employment subsidy. Wage cost subsidy (up to 100% of wage cost). On-the-job-support: individual job coach. Work bonus for goods.	Network of local resources to assist employment services. Reduction of social security charges. Possibility of flexible working hours.	Subsidised employment (up to 24 months).	Work with wage subsidy (up to 100% of wage cost for severe disabilities).	Wage subsidies: the job introduction scheme encourages employers to take on a disabled person for 6 weeks. Tax credit to help the disabled return or take up work by rising earnings.
Start-up grants.	Grant to set-up own business.	Investment allowance for start-up.	Start-up grant for a business or trade.	

Sources: Bergeskog, 2001; Brunel – National Reports, 2002; European Foundation for the Improvement of Living and Working Conditions, EIROnline; M. van Lin et al, 2002.

**Table 19 Personal support, workplace adaptations and related measures (main national measures)**

B	DK	D	EL	E
Grant for work adaptation. Grant for tutor in an enterprise. Personal support at the workplace.	Personal assistance to employed or unemployed. Grants to employers for the salary of a personal assistant. Workplace adaptation and technical aids.	Grants for workplace accommodation. Job coach ensures that support is tailored to specific needs. Support to person/group in companies.	Ergonomic adaptation of the workplace.	Subsidies for technical aids.
F	I	IRL	L	NL
Actions to keep employment.	Subsidy for the workplace adaptation. Subsidy for the removal of architectural barriers at work.  Subsidy for the set up of teleworking technology.	Workplace equipment adaptation grant. Employment support scheme (job coach): match job opportunities with the person's abilities.	Workplace subsidies.	Transportation and communication provisions.  Individual tailor-made budget REA.
A	P	FIN	SW	UK
Subsidy for work place adaptation.  Job coach & job assistant.	Grants for workplace adaptations. Personalised attendance in the company.	Personal assistance in the workplace. Technical aids and adaptation of the workplace.	Financial support for personal assistance (introduction and follow-up at work).  Grants for workplace adjustments and work-aids.	Subsidies for equipment and adaptation to premises. Job start payments to fund support. Network of local job brokers providing individualised assistance.

Sources: Bergeskog, 2001; Brunel – National Reports, 2002; M. van Lin et al, 2002; MISEP, 2002; P. Thornton, 1998; C. Russell, 1998.

## Quota schemes

An obligation to employ a minimum ratio of people with an illness or disability exists in ten Member States (see Table 20). In computing the effective figure, it should be noted that certain categories count for more than one unit (e.g. severe disability, young persons, elderly people, etc.).

Despite criticisms of quota schemes, they remain the main visible, permanent policy in support of people with an illness or disability in the majority of Member States. According to available information they have had some success in Germany and to a lesser extent in France and Austria. In all cases the targets are far from being reached, despite the fact that the quota ratio is very low in some countries (Spain, Ireland).

In general, employers who do not comply pay a compensatory levy, which is used to finance measures in support of people with a chronic illness or disability. Other forms of exemption include:

- if the company signs a supply or service contract with a sheltered workshop (e.g. Spain, France);
- if social partners agree to establish a gradual plan (e.g. France).



Table 20 shows that there is no penalty in some countries. In order to increase the efficiency of the scheme without imposing additional regulations on companies, an alternative could be to ask them to produce an annual report in which they show the number of people with a chronic illness or disability that they employ. This administrative obligation to report could be organised at a European level, independently from a quota obligation. Some kind of sanction could be imposed in case of non-compliance (e.g. exclusion from public procurement, refusal of general financial assistance, etc.).

An obligation to report would have more chance of success to if it also covered the public sector. An obligation covering only private companies could put them at a disadvantage compared with public companies. An obligation to report quantitative indicators in order to assess the employment situation of men and women has been adopted, for example, in France, and it does cover the public service<sup>15</sup>. It includes indicators for people with disabilities. Such experiences could provide interesting lessons for developing similar obligations relating to people with disabilities.

The quality of jobs offered has always been the subject of criticism by NGOs. They believe that very often people with a chronic illness or disability are offered jobs that reinforce existing stereotypes and stigmas. Just as there are certain jobs traditionally done by women, so there are jobs associated with disability, such as parking attendants, concierges and tobacco retailers.

The OECD believes that employees who become disabled and are eligible to count towards the quota are more likely to be kept in a job. But quota schemes give little incentive to employ new applicants once the quota figure has been reached (OECD 2002). There is no significant difference between small and big companies in employing people with a chronic illness or disability – at least in Germany, for which there is reliable data.

In the public debate on this issue it is often argued that the quota system has a negative impact on job creation in small firms. It is argued that firms near the threshold (e.g. 19 workers in Germany) that do not employ people with disabilities will not react to a 'positive demand shock'. If they face a small increase in permanent demand, they could not hire an additional worker, unlike those employing 18 or 20 people. If they do hire an additional worker they will be subject to the quota obligation. This means that if they hire a non-disabled person, the cost will be the wages of the new worker plus the penalty for not respecting the quota obligation.

An econometric investigation of German firms employing a number of workers near the threshold of 15 employees (which applied before 2000) indicated that there was no such disincentive (J. Wagner et al, 2001). Small firms at the margin of the threshold were behaving just like other firms.

Quota schemes also exist in some of the candidate countries (e.g. Czech Republic), and are similar to those of the Member States.

The future of the quota schemes is uncertain. They are criticised both by opponents of regulations

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<sup>15</sup> Décret n° 2002-230 du 15 février 2002 (Bulletin Officiel n° 2002-8).

and by disabled people's organisations. The former argue that regulations impede the creation of new jobs. The latter take the view that anti-discrimination policies will re-establish equal opportunities and so enable people with disabilities to take their fair share of employment. For different reasons neither group takes account of the disadvantaged position of people with disabilities in the labour market and the need for a redistributive mechanism that ensures equity and social responsibility.

## Sheltered employment

Sheltered employment is open to people who, because of their disability, are unable to obtain or keep a normal job, whether supported or not. Sheltered workshops are productive units, which provide work to people with disabilities and prepare them for a job in the ordinary labour market. They offer the necessary help for people with disabilities, notably rehabilitation services and vocational training. Sheltered work sections can be found within ordinary firms.

Sheltered workshops should be distinguished from work centres receiving people who cannot work in sheltered workshops or in an ordinary working environment, but who are nonetheless able, with medical and social support, to carry out a remunerative professional activity. Such special centres of employment and work assistance centres are found notably in Spain and France. Social cooperatives play an important role in Italy. Many of the 6,000 cooperatives employ disadvantaged people. Therapeutic centres may provide valuable activity, but from a therapeutic perspective. Exit rates in such cases are very low. These centres are not included in the statistics presented below.

Sheltered workshops currently employ about 500,000 people in the European Union (Table 21). Critics argue that there is a low rate of exits from sheltered workshops to open employment. For example, every year in Sweden 3% to 5% of the employees in sheltered employment leave to go to an 'open' employer. In the remaining countries it amounts to less than 3% (Belgium, France, Spain, Ireland and the UK-Scotland) (L. Visier, 1998). This could be due to the economic constraints put on such workplaces. Competition and an obligation to ensure the financial viability of the unit might put pressure on these centres to keep their best workers.

Apart from strict financial reasons social and psychological factors should be taken into account. Those with severe disabilities often feel marginalised and insecure in open employment and may prefer to stay in a sheltered environment where they feel part of a social group. In such cases changes in attitude should be the concern of society in general rather than the managers of sheltered workshops. Most of those in sheltered workshops are young people with a mental retardation. Those with a psychological impairment are also over-represented (S. Grammenos, 1995). Drug addicts can be found in sheltered places in some countries (Finland).

There is a growing demand from sheltered workshops to be considered as normal companies. In many countries the social protection schemes are identical to those for the open sector (e.g. Germany, Spain (CEE), France (AP), Great Britain, Portugal and Sweden) (L. Visier, 1998). Many of these workshops have accepted competition rules and try to behave as ordinary companies with a supplementary social task. The label 'social company' is often used. Following a judgement by the European Court of Justice (Betray case, 344/87), people in sheltered workshops who are governed by labour legislation acquire the status of workers. However, this does not apply to establishments that are governed by socio-medical legislation.

Table 20 Quota schemes

	DK	D <sup>1</sup>	EL	E
Rate		5%	3%, 4%	2%
Company size		≥20	≥50: 3% public: 4%	≥50
Sector		Private Public	Private Public	Private Public
Penalty / Levy		Yes	Yes	No
Law		2000 Schwb BAG	Law 2643/98	Royal decree 27/2000
Application		3.9	Poor	Poor
Notes	Priority access to employment in the public sector is rarely used.	Severely: if degree ≥50. Equal status: if degree 30% to 50% and if they are not able to take up or keep a job. Registration. Application: 3.9 (1997)	Under revision. Beneficiaries include civil and war disabled. There is an additional rate of 5% (public sector: 4%) for other groups.	Previous law was ignored by employers.
	F	I	IRL	L
Rate	6%	7%	3%	2%, 4%, 5%
Company size	≥20	15-35: 1 disabled 36-50: 2 disabled ≥50: 7%	–	≥50: 2% ≥300: 4% public: 5%
Sector	Private Public	Private Public	– Public	Private Public
Penalty / Levy	Yes	Yes	No	Yes
Law	Law 10 July 1987	Law 68/99	Not compulsory, 1976	Law 12/11/1991
Application	4%	New law aims to better results.	1.8%	Never applied
Notes	Employment rate of disabled: 2.7%. In fact, severe disabled count more than one unit in the quota. Registration.	Beneficiaries: work reduction capacity ≥45 or disabled at work with a disability rate of ≥33%. Companies with ≥50 employees have to employ 1% of widows, orphans & refugees.	In the civil service 2.6% are disabled workers (2000) and 1.7% in public services (1998).	Effective quota (97): Municipalities: 0.82%. Public sector: 2.83%.
	NL	A	P	UK
Rate	5%	4%	5%	
Company size		≥25		
Sector		Private Public	– Public	
Penalty / Levy		Yes	No	
Law	REA July 1998	Disabled persons employment Act, 1989.	Law 29/2001	
Application	Legislation in preparation.	2.6%	Poor	
Notes		Beneficiaries are registered persons. Minimum degree of disability: 50% (on medical criteria). Quota obligation fulfilled at 2.6% (1999).	Requires a 60% degree of disability.	The Quota was replaced by Disability Discrimination Act in 1996.

Sources: M. Amar et S. Amira, 2002; Bergeskog, 2001; Brunel – National Reports, 2002; Federal Employment Service, 2002; Ministre aux handicapés, 1997; M. van Lin et al, 2002; MISEP, 2002; P. Thornton, 1998; C. Russell, 1998.

<sup>1</sup> The rate will become 6%, if the objective of reducing disabled unemployment by 50,000 is not achieved

The following table shows that the number of sheltered places has decreased, notably in countries where it had been relatively high (Belgium, Netherlands, Finland and Sweden). In some countries (Greece and Portugal) the sector is at a teething stage. Experience gained elsewhere should be evaluated in these two countries.

Sheltered workshops in Central and Eastern Europe face many difficulties due to the lack of competitiveness and lack of subsidies. The introduction of management methods close to those of private companies could help them in the long run, but in the short term they need significant funding to undertake the necessary changes.

**Table 21 Sheltered workshops in the EU (employing about 500,000 workers)**

	B	DK	D	E	F	IRL	I	L	NL	A	P	FIN	SW	UK
Current number	17,978	4,700	195,000	37,529	96,162	3,980	11,996	273	80,000		707	9,400	31,003	22,000
Per 1000 labour force	4.13	1.64	4.92	2.28	3.53	2.36	0.51	1.13	9.71		0.14	3.65	7.10	0.70
Year	1998	1999	2001	1998	1999	1999	2000	1998	2001		1998	1999	2001	1997
Number in 1991	20,506	7,764	137,000	10,485	96,174	2,970	3,500	100	82,066	1,000	1,062	11,000	34,000	14,162 (+32,000)

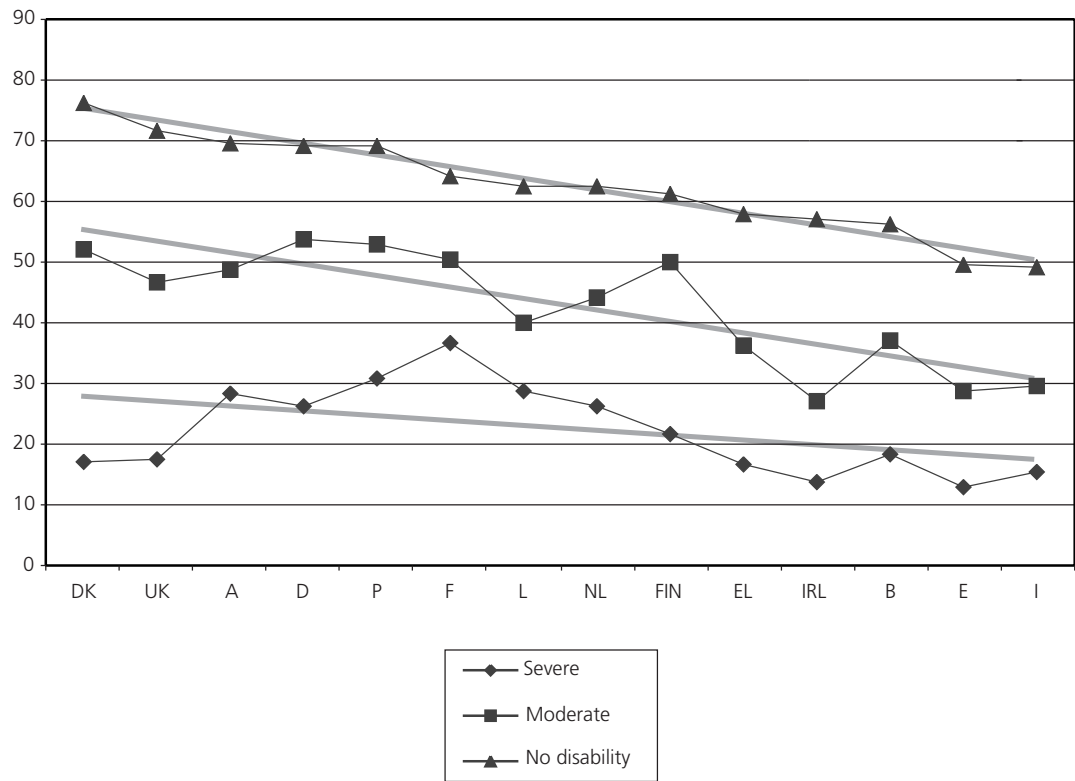
Source: M. Amar et S. Amira, 2002; Bergeskog, 2001; Brunel – National Reports, 2002; Federal Employment Service, 2002; S. Grammenos, 1995; Ministre aux handicapés, 1997; MISEP, 2002; NOSOSCO, 2001; M. van Lin et al, 2002; P. Thornton, 1998; C. Russell, 1998; L. Visier, 1998.

## Elements for an evaluation

In the following figure Member States are ranged according to the employment rate of non-disabled persons. It should be noted that:

- Denmark and the United Kingdom are characterised by a clear relative disadvantage for people with disabilities in the labour market. This could be the result of underdeveloped active policy measures, and an almost exclusive policy of income support, notably in Denmark.
- Greece, Ireland and Spain are also characterised by a relative disadvantage for people with an illness or disability, but this could be due to underdeveloped sheltered employment and the ineffective or non-application of the quota system.
- Countries with positive discrimination measures, including a quota scheme (Germany, France and Portugal) or an active policy at a local level (Finland) achieve relatively better results.
- A combination of the quota system and a reasonable sheltered sector explains the relatively better situation of both moderate and severely disabled people, notably in France.

Figure 27 Employment rates by disability status and country



Source: Eurostat, 2001. Survey data.

# Reintegration at work of people who become ill or disabled

It is interesting to note the ILO Convention No 159 and Recommendation No 168 concerning vocational rehabilitation and employment of disabled persons, adopted in June 20, 1983 (ILO, 1998). The convention a) defines the term 'disabled' and the concept of vocational rehabilitation; b) lays down the principles of a national policy on vocational rehabilitation and employment of disabled persons (equality of opportunity and participation); provides for the consultation of social partners; and c) deals with vocational rehabilitation and employment services.

The majority of the Member States – not Austria, Belgium, Italy, Luxembourg, Portugal and the United Kingdom – have adopted the Convention (European Commission, 1999). It is about people 'whose prospects of securing, retaining and advancing in suitable employment are substantially reduced as a result of a duly recognised physical or mental impairment'. The Recommendation lists measures that enable these people to be integrated into ordinary working life. It recommends the participation of disabled people's organisations and social partners.

Despite these orientations, many countries consider rehabilitation as an individual medical problem. Consequently, they stress individual limitations and aim to raise the person's condition to a norm. Rehabilitation is often organised in medico-pedagogical institutions and the process is reduced to a functional rehabilitation programme. Social and professional aspects take a minor role. For example, work adaptation and housing adaptation are seldom taken into account. Architectural and other forms of barriers are seldom incorporated.

So it is interesting to note the recent changes in German law that distinguish:

- medical rehabilitation (treatment by doctors, etc.);
- occupational rehabilitation (help with acquiring or remaining in employment, vocational training, etc.); and
- participation in social life (education, housing, autonomy, etc.).

Big differences between Member States are apparent in dealing with accidents and occupational diseases (D. De Bruck, 2001):

- In Germany all aspects are treated by the same organisation, which is administered by social partners. In about 80% of cases the worker keeps or gets a new job. In Austria also, one body organises the whole rehabilitation process.
- In Sweden it is up to employers to manage the rehabilitation process. The goal is to enable victims of work accidents to regain their jobs.
- In Denmark and Finland rehabilitation is part of general assistance for disabled people. Local authorities play an important role in professional and social rehabilitation.
- In France social security funds and socio-medical services examine the options: a) firing, b) re-education within the company according to a negotiated plan between the victim, the Fund and the employer, or c) special rehabilitation with a subsequent attempt to reintegrate the worker into the company.

- In Belgium the physician of the Fund may ask employers to examine the possibility of reintegrating workers into their jobs, if that is practical. During the period 1987-1997, 45% of the victims of occupational sickness entered unemployment.
- In Spain legislation stipulates that vocational rehabilitation can be available inside the firm. In such cases a special contract is agreed between the worker and the employer.

The previous schemes do not cover all people who acquire an illness or a disability. Social security schemes often take into account the origin of an illness or disability, the social security status, etc. From this point of view it is interesting to note the German case, where the social code considers rehabilitation as a social right, independently of the cause of the disability. The principle of 'rehabilitation before pension' is applied by Germany and Austria. This means that an application for an invalidity pension is also treated as an application for rehabilitation.

The next table shows that there is a wide range of nominal measures in the Member States, aiming to reintegrate people who acquire an illness or a disability. Some of them are legally binding, notably:

- in Spain, which stipulates reintegration into the same post or, when this is not possible, into an inferior category with the same remuneration; a worker has priority for vacancies in the same company;
- in Italy, where employers have to assign equivalent tasks to disabled people, or, if this is not possible, lower graded tasks but under previous conditions;
- in the Netherlands, where a new law obliges companies to make more efforts to retain employees who have suffered an illness or disability;
- in Austria, where an employee may not be assigned to a job below his/her qualifications;
- in Sweden, where the employer has to make reasonable adjustments to the work (place) or, if possible, provide a different job in the same company.

These are only nominal obligations in most cases. For example, in Spain the law requires reintegration but does not penalise companies that do not comply with the legislation. In the Netherlands as many as 80% of employers do not consider disabled employees for new positions (European Foundation for the Improvement of Living and Working Conditions, EIROOnline). In other countries compliance is weak. The OECD (2002) notes that many regulations are difficult to enforce, despite the possibility of imposing sanctions on employers who do not comply. In fact, most regulations contain wording that is open to interpretation.

In Sweden, the government is considering tightening up the regulations governing employers' obligation to participate in the rehabilitation process. Experience in the United States indicates that the Americans with Disabilities Act (ADA) has had a significant impact on job retention by obliging employers to accommodate returning workers. The EU Anti-discrimination Directive should have the same impact. A similar role is played by the quota system.

A study of a cohort with lower back pain reveals that large differences in return-to-work rates exist between countries (I. Zeitzer, 2002). Within a two-year period return to work was 40% in Denmark

and Germany, 60% in Sweden and over 70% in the Netherlands. Of those who resumed work, about 50% did so with their former employer in Denmark, 70% in Sweden and over 80% in Germany and the Netherlands. Active policies combined with compulsory legal instruments may explain the relatively high return rate to previous employers in the last three countries. It is interesting to note that those who returned to the same employer in Denmark had to accept less qualified work.

Globally, however, the rate of return to work is low in Denmark and Germany. The study reveals that old age and limited education are factors that play against return to work. By contrast workplace adaptation and flexible working hours favour work reintegration.

The level of education is a good proxy for working conditions. This indicates that return to work is low in jobs with bad working conditions – a finding that has been supported also by other studies (J. Høgelund, 2002), which find that:

- employees from companies with a high disability benefit incidence rate have a relatively low chance of return to work; and
- males employed in sectors with physically demanding jobs have a relatively low chance of return to work.

The majority of people with an illness or disability are aged 50 or more. For this age group the priority should be to keep a job or use their experience in a similar job. Many of those who keep working change jobs within several years of the onset of their poor health, suggesting that changing jobs is an important way for older people to stay in work (J. Bound et al, 1998). In fact keeping the same job could damage their health further. Consequently they search for jobs that are compatible with their limitations.

A low return rate may be the result of:

- a refusal by companies to reintegrate people with disabilities;
- technical limitations and health protection standards; or
- an absence of job vacancies compatible with the limitations; in such cases returning to previous jobs could worsen the health of disabled people.

In principle, reintegration into the same company ought to cover everyone without distinctions between the origins of their disability (work accident, home accident, etc.). In this case public policy could help companies in their efforts to reintegrate people with disabilities into their previous job, through subsidies for technical aids, workplace adaptation, etc.

Work accidents and occupational diseases present a specific problem. As was noted above, companies with bad accident records ought to pay fines or differentiated premiums. The fine or differentiated premium ought to reflect the cost that is not otherwise borne by the company and is supported by the community (pensions, rehabilitation, etc.). This ought to re-establish the principle of fair competition between companies and eradicate the unfair competitive advantage of companies with bad accident records.



**Table 22 Reintegration measures (main measures)**

<b>B</b>	<b>DK</b>	<b>D</b>	<b>EL<sup>1</sup></b>	<b>E</b>
Progressive return to work if possible. Training in another job is financed by the health insurance.	A financial pool helps disabled to maintain their jobs (training, aids, ...).	Occupational adaptation according to skills and capabilities. Step-wise rehabilitation.  Preferential selection for in-house and support for external training measures.  Training allowance, technical aids and transport assistance. Integration grant to employer.  The retention of an employee who becomes disabled counts for the quota.		Reintegration into the same post or, when this is not possible, to an inferior category with the same remuneration as before, and which cannot be reduced by more than 25% if performance was reduced, but weak compliance.  Priority for vacancies in the same company.  Social security subsidies to employers.
<b>F</b>	<b>I</b>	<b>IRL</b>	<b>L<sup>1</sup></b>	<b>NL</b>
The quota encourages retention and rehabilitation plans.  Grants for work adaptations.	Employers have to assign the disabled equivalent tasks, or, if not possible, lower graded tasks but under previous conditions.	Grants for retaining people who acquire a disability.		Replacement budget.  New law obliges companies to make more efforts for retention. Premium differentiation.
<b>A</b>	<b>P</b>	<b>FIN</b>	<b>SW</b>	<b>UK</b>
An employee may not be assigned to a job below his/her qualifications.	Workplace adaptation.  Part-time work.  Leave to train for other job.	Financial support to acquire tools and machinery and to establish or transform an own enterprise.  Medical rehabilitation to keep the job.  Work trials and work adjustments.	The employer has to provide reasonable accommodation of the work (place) or, if possible, a different job in the company.  Rehabilitation benefit to pay education, transport, etc.	The Disability Discrimination Act provides that disability may not be a reason for dismissal.

<sup>1</sup> = Information not available.

Note: The table does not include rehabilitation benefits and pensions (i.e. DK: 20,864; FIN: 10,212; SW: 13,332; end 1998;

Source: NOSOSCO).

Source: OECD (2002), Brunel.

The Council, in 1990, adopted a Resolution concerning integration of children and young people with disabilities into ordinary systems of education. The Resolution, which is not binding, encourages integration of pupils and students with disabilities, in all appropriate cases, into the ordinary education system (Council, 1990).

The European Commission (2001) notes that Member States are recognising the importance of integrating disabled children with special needs into the mainstream education system:

- In the United Kingdom the 1995 Disability Discrimination Act has now been extended to education.
- Austria extended its specific policy on the integration of school children with special needs up to the ninth school year, from 2001-2.
- In the Netherlands parents have had a choice since 2001 of placing children with disabilities in special schools or in mainstream schools. A sum of money is available for the school to make special adaptations for the pupil.
- In Germany and Italy initiatives have been taken to integrate disabled pupils into ordinary schools. Depending on the nature and degree of the disability, special pedagogic support is provided.
- Spain provides additional support services in education. Plans to extend support programmes for deaf people and people with a hearing impairment at all levels of education have been developed.

For purposes of comparison one has to distinguish between:

- special education in special schools;
- special classes in ordinary education; and
- ordinary classes in ordinary schools.

In Denmark general practice favours special classes in ordinary schools. The education law provides that teachers and pupils should negotiate a plan. Local authorities must ensure that all children have a place in ordinary classes or equivalent ones. Support services include psychologists, counsellors, medical services and ergotherapy.

In Ireland an initiative to guarantee effective free choice has been taken. The goal of the Irish law is firstly to organise the conditions that allow a choice of school according to ability, and secondly to implement this choice. The Education Act, 1998, stipulates that recognised schools shall use their available resources to ensure that the educational needs of all students, including those with a disability or other special educational need, are identified and provided for. Consequently, children with special needs attending ordinary schools will have automatic access to special teaching support and, if necessary, to the child care support needed to achieve their potential within the education system.

Similarly parents in Austria have had, since 1993, the choice in primary level education (the first four years) between integrated and specialised education. The education reform in 1996 enlarged

the possibility of 'inclusive' education to the first cycle of the secondary level. However, parents do not have the same options here as in primary school.

National policy in Italy gives a high priority to mainstreaming and local synergy has been sought. In order to achieve the integration of disabled young people into schools, every provincial education department has to set up a working group in which disabled people's organisations participate.

In the United Kingdom pupils with special needs in ordinary classes receive external support. Each school has to designate someone to coordinate the courses offered to pupils with special educational needs. This person develops the school's strategy and monitors different actions inside and outside the school.

Mainstream schooling means that special schools ought to be the exception and concern only pupils with severe disabilities. The experience of turning these schools into resource centres for support services (Denmark, Finland and Sweden) ought to be looked into by other Member States. In fact ordinary schools often advance the lack of specialised support for their disabled pupils as one important reason for inaction. Resource centres could provide this expertise to ordinary schools.

Special support could include:

- external support to the school: this could include provision of specialist services like physiotherapy, psychology and counsellors in pedagogy;
- internal support: special educators, coordinators of the different support services, etc.

Keeping children with disabilities in an ordinary school and in their family environment requires the development of the necessary support services for the family.

Most available evaluations are of a qualitative nature. They analyse the organisation and implementation of a programme and ask strategic policy-makers or the beneficiaries themselves to give their personal assessments.

For example, the Greek National Confederation of Disabled People (2002) undertook an assessment of national policies for social inclusion in Europe. They asked a representative set of organisations of people with disabilities and main actors in the field to evaluate the effectiveness of their government policies for social inclusion on a scale of 1 (minimum) to 10 (maximum). This is a subjective evaluation and comparison between countries is not desirable as people may use different references for the evaluation. However, in general they do not seem to assign high values and disabled people themselves do not seem to be very satisfied with current policies.

In the United Kingdom the job introduction scheme encourages employers to take a person with a disability for six weeks. The employer receives a subsidy. An evaluation through interviews with employers, participants and public officers showed that (A. Bergeskog, 2001):

- the scheme is quick and simple to set up, which is an advantage;
- it helps employers to assess, with a minimum risk, the suitability of an employee with a moderate disability; but large employers think that the subsidy is too small; and
- the scheme draws attention to a disability that the employer might not otherwise have been aware of.

The fact that some programmes may increase the concern of employers and lead to stigmatisation is found in many studies treating disadvantaged groups (T. Magnac, 2000). In the same spirit, employers interviewed in Belgium and Austria consider subsidies as a way to reduce disadvantage and not as a real advantage.

Another method consists of measuring the impact of the programme by comparing expected and effective results or by comparing the employment rates of participants and non-participants in the programme. These assessments focus on the short term and there is little information on the long-term impact.

The 'naïve' approach consists in reporting the number of beneficiaries who found a job at the end of a programme and comparing it with data for similar groups or national aggregates. Most of the evaluations undertaken for the European Commission, for example the evaluation of European Social Fund actions (European Commission, 1997), are of this type.

In the United Kingdom a follow-up of a training scheme for people with disabilities, aiming to prepare them for a job in the open labour market, found that (A. Bergeskog, 2001) the figures for those who had a job, six months after completion of the programme, were:

- 34% of all participants;
- 43% of participants with physical disabilities;
- 27% of participants with mental health difficulties; and
- 31% of participants with learning difficulties.

The study confirms previous results, arguing that people with mental problems are the most disadvantaged and that current measures have little impact upon them.

This method has been criticised, mainly because it entails a 'selection bias'. Most agencies that implement these programmes have a limited number of places and choose the best candidates. Consequently, any difference in the results might be caused, not by the programme itself, but by characteristics existing before the start of the programme. In other words, even in the absence of the programme these people might have found a job.

Advanced econometric studies using data from (panel) surveys aim to eliminate this bias by using, for comparison, individuals who applied to a programme and were rejected, or individuals who did not apply to the programme or samples of persons similar to trainees (J. J. Heckman and V. J. Hotz, 1989). The comparison aims to define a group that is judged to be comparable with participants in a programme, except for the fact that they have not participated in it.

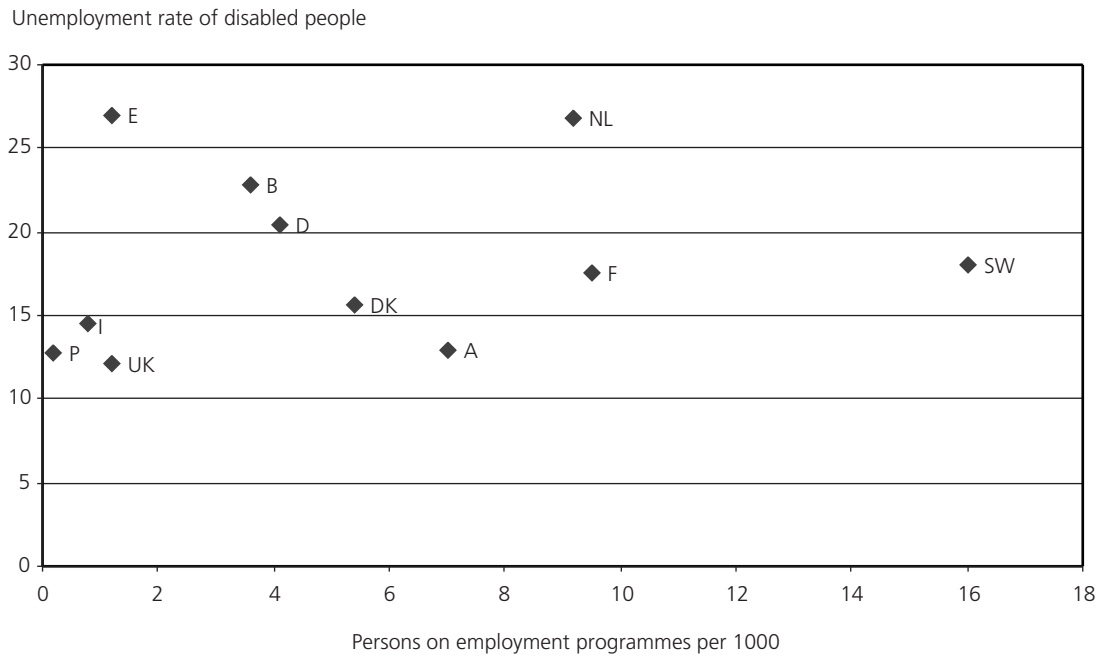
Most available econometric studies measure how transition probabilities towards a job are affected by previous participation in a programme. They measure the impact of spells in training programmes or work experience programmes on the probability of moving into employment.

A similar approach was used to evaluate the French scheme 'Minimum Insertion Income', which aimed to reach disadvantaged people. Those with disabilities were over-represented. In fact 32% of unemployed participants had a work-limiting health problem, while only 12% of all the unemployed have a similar problem (L. Rioux, 2001). The programme requires applicants to participate in all actions necessary for their socio-professional integration. The claimant and the social worker agree on a re-insertion plan. Despite its compulsory nature only a proportion of the beneficiaries signed a plan. Evaluation of the programme shows that those with work-limiting health problems or disabilities have less chance of signing a plan, meaning that the scheme does not take full account of their specific needs (J. P. Zoyem, 2001). The study confirms the results of similar research in Belgium, which found that entering into supported employment is equivalent to deskilling, which pushes the beneficiary into the sector of precarious employment.

It is important to stress that active policies might aim at creating new jobs but also aim at equity targets. In the latter case the objective is to achieve a redistribution of existing jobs in favour of groups that are strongly under-represented. The quota schemes aim to achieve such a distributional equity.

The next figure (28) indicates that active policy has a limited impact on the unemployment rate of people with a chronic illness or disability. This does not mean that the policies followed are ineffective. A successful active policy could encourage many inactive people to enter the labour market and search for a job. The new arrivals in the labour market could compensate (partly or totally) for the numbers who leave unemployment to take up a job.

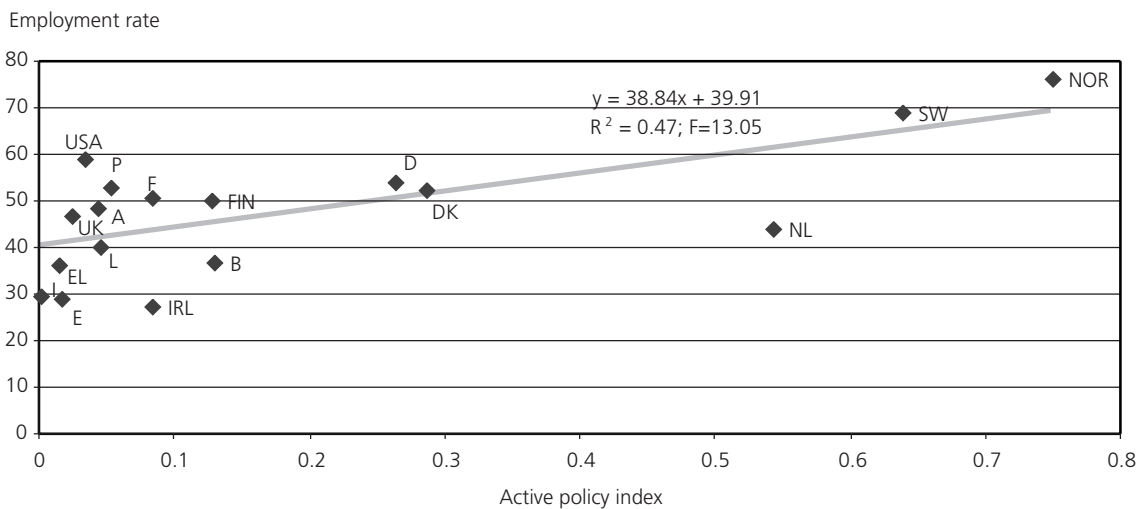
**Figure 28 The impact of policy on the unemployment rate of disabled persons**



Source: OECD, 2002; J. P. Martin, 2000.

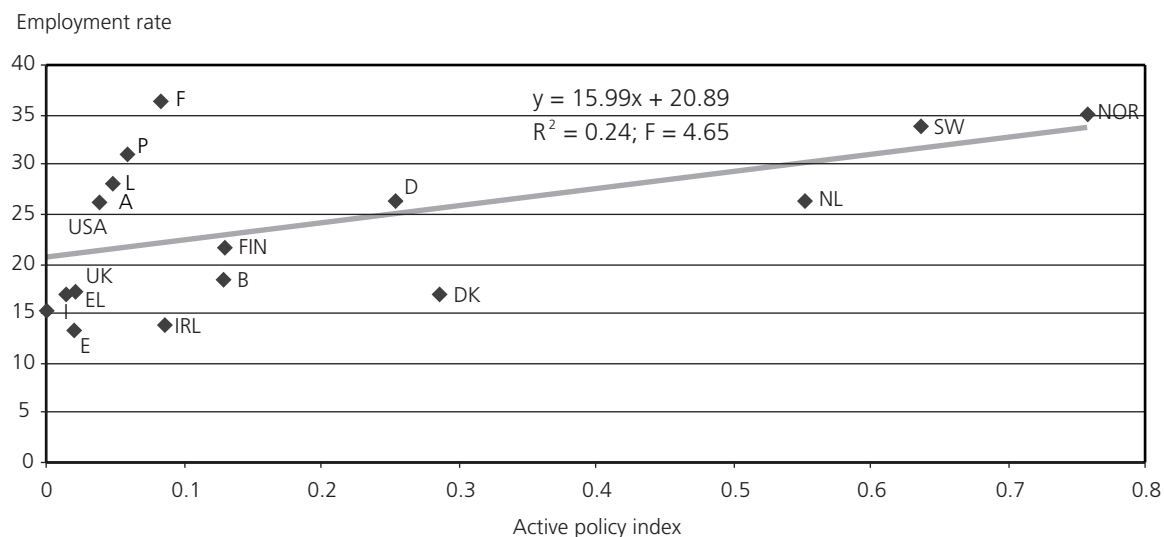
The next two graphs (Figures 29 and 30) present the impact of active policies on the employment of people with an illness or disability. They indicate that the impact is very weak<sup>16</sup>. It is stronger for those with a moderate disability than for the severely disabled. In general, the reported countries spend about 1.1% of their Gross Domestic Product (GDP) financing active labour market policies. On average 12% of this is spent on specific measures in support of the disabled.

**Figure 29 The impact of active policy on the employment rate of people with a moderate disability**



<sup>16</sup> The estimated elasticity is about 10%.

**Figure 30 The impact of active policies on the employment rate of people with severe disabilities**



Source: OECD, 2002; J. P. Martin, 2000.

Note: The active policy index measures the cost of active labour market policies in favour of persons with a chronic illness or a disability as a percentage of gross domestic product.

The graphs show that there is a minimum level below which a policy has no significant impact. In fact under the threshold of 0.1% of GDP there is no relation between active policy and the employment of disabled people. This indicates that adequate measures could need a minimum level of resources.

In order to achieve this minimum level of resources public policies ought to favour:

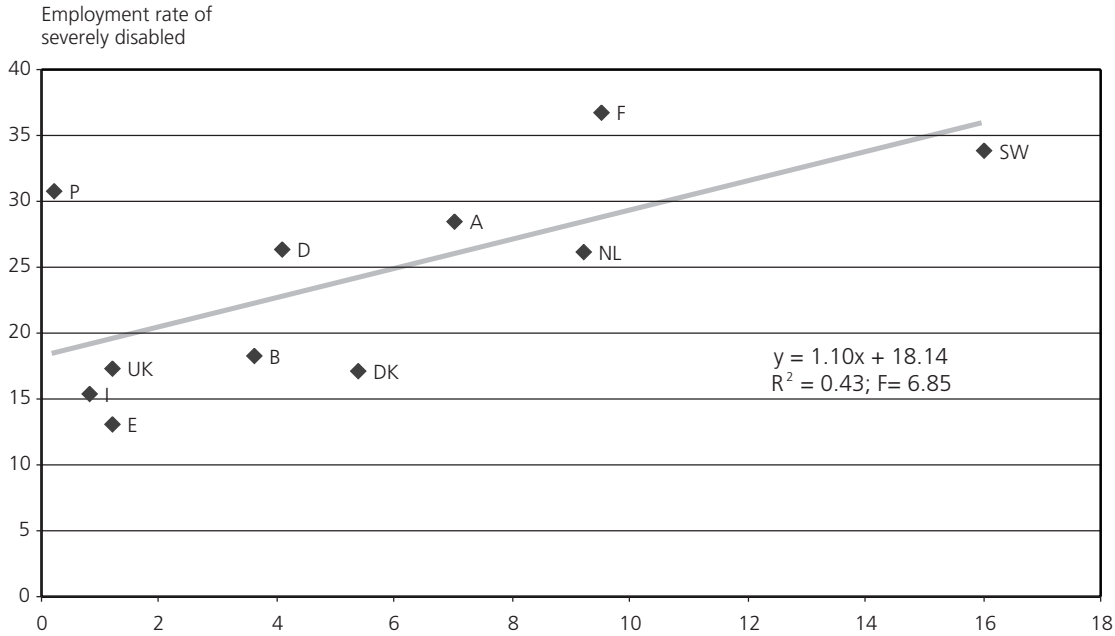
- public-private partnerships, and
- coherence and coordination of national policies at different levels.

This could be difficult to achieve in the new candidate countries, where the proportion spent on people with disabilities is relatively low and the existing infrastructure underdeveloped. In Slovakia, for example, it was about 0.01% (O. Ochotnický, 1997). Nine of the Member States and those about to become members are below the target of 0.1% of GDP.

The target of 0.1% does not mean necessarily an increase in available resources but a better coordination and targeting. The first step requires better coordination and coherence of available services. In some cases it might be enough to organise existing services and infrastructures better.

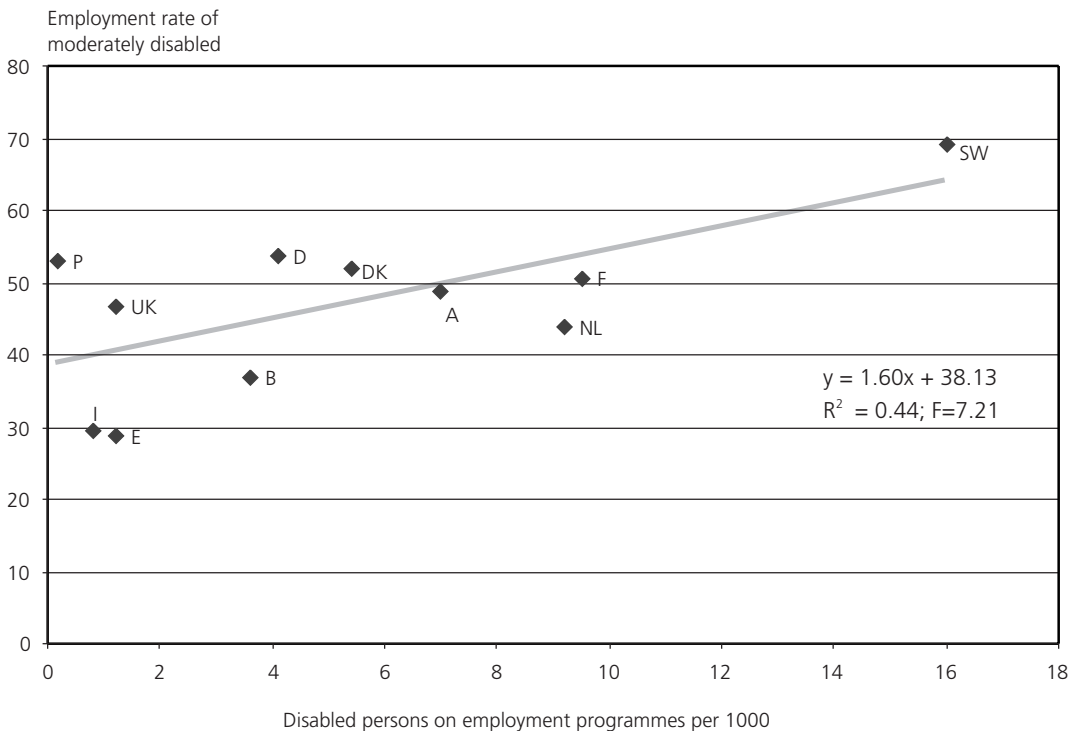
Figures 31 and 32 present the impact of public programmes on employment. They show that employment programmes are an important element in the employment of people with disabilities. Again the employment rate of people with moderate disabilities seems to be more sensitive to public policy than that of more severely disabled people. The figures use a global index for public policy and do not distinguish the effectiveness of individual measures (wage subsidies, training, etc.).

**Figure 31 The impact of public programmes on the employment rate of the severely disabled**



Source: Eurostat, 2001; OECD, 2002.

**Figure 32 The impact of public programmes on the employment rate of the moderately disabled**



Source: Eurostat, 2001; OECD, 2002.



Evaluation of general wage subsidies in Belgium, Ireland and the Netherlands reveals that they constitute a 'windfall effect' for employers and that the substitution effect amounts to about 90%. This means that only 10% of subsidised jobs are additional, new jobs (J. P. Martin, 2000). Similar results have been found in Denmark and Sweden. Belgian data indicate also that subsidised in-company training and pure subsidies have little impact on the length of hiring. In the case of pure subsidies the variable 'disability' has a negative sign, as expected, but is not significantly different from zero (B. Van der Linden, 2000). As noted above, disability or functional limitations are not always significant, notably when collinear variables like education or age could discount part of its effect.

The traditional criticism, that wage subsidies and other measures could lead to substitution effects, ought to be taken into account even in the case of a policy aiming to achieve an equitable distribution of existing jobs. In fact, substitutability is high between disabled people and low educated, unskilled workers. Such policies could simply replace one form of inequity by another form.

On workplace adaptation, it is important to note that the take-up of subsidies is very low in the Netherlands and Sweden, according to the available information. A survey in the Netherlands found that employers had used subsidies for only 0.06% of their employees (P. Thornton, 1998).

Evaluation of policies on disadvantaged people (J. P. Martin, 2000), shows that successful training programmes ought to:

- have precise targets for participants;
- favour programmes with relatively small numbers; and
- include a significant component of on-the-job training and establish strong links with local employers.

Precise definitions of the target group risk leading to stigmatisation. It discourages workers from participating and is associated by employers with low productivity and a low level of involvement in the labour market.

Ensuring that disability is taken into account in all relevant sectors of policy formulation means considering the needs of disabled people when elaborating these policies. This approach requires action at an early stage, often in cooperation with those who will be affected by the policies proposed. Member States should make sure that services and programmes are delivered in a way that recognises and accommodates the specific needs of disabled people. In this way people with disabilities could have equal access to mainstream services and programmes that serve the whole population.

In order to achieve this goal, policy-makers should plan strategically at the conception and design stage of policies. They ought to anticipate barriers that could prevent disabled people taking full advantage of the proposed schemes, and to propose solutions that overcome these obstacles.

This chapter looks at national structures that ensure the coherence of national actions. But there is an important limitation: these structures focus on specific measures in support of people with disabilities. As a result they miss the mainstreaming approach. Structures that involve representatives of people with disabilities are outlined as their participation may enhance the success of these policies. In fact they are in the best position to know the needs of disabled people and assess the likely efficiency of proposed measures.

In Belgium the Higher National Council, an advisory body at federal level, advises different ministries on measures that should be taken to help people with disabilities. In Denmark the National Handicap Council advises the different ministries on matters relating to disability. At federal level in Germany, the Federal Ministry for Labour and Social Affairs has assumed responsibility for coordination. The Ministry is supported by the Advisory committee for rehabilitation of people with disabilities. Other federal ministries are also involved where appropriate. The advisory committee includes representatives of employees, employers and disabled people's organisations.

In Greece the National Confederation of Disabled People is the government's social partner in matters relating to people with a disability. In Spain a joint committee of representatives of the Ministry of Labour and Social Affairs and the Council of Representatives of Disabled People aims at improving coordination between public administration and disabled people's organisations. In France, when ministers draw up policy proposals, they consult either the National Advisory Committee for Disabled People or the Council for Occupational Rehabilitation, depending on the subject.

In Ireland the main terms of reference of the Commission on the Status of People with Disabilities are to advise the Government on practical measures and to ensure that the needs of people with disabilities are met in a cohesive, comprehensive and cost effective way. In Italy the Standing Committee on Relations between the State and the Cities is assisted by representatives of the Italian Municipalities Association, the social partners and NGOs. In Luxembourg the Council for Disabled People is an advisory body for policies on people with disabilities.

In the Netherlands the Inter-ministerial Committee coordinates measures taken by the various ministries. The Inter-ministerial Committee consults, on a regular or ad hoc basis, organisations for the physically and mentally disabled, and the 'private initiative', the Netherlands Disability Forum.

In Finland the National Council on Disability is attached to the Ministry of Social Affairs and Health. The aim of the Council is to combat discrimination and to reduce prejudice against people with disabilities. In the United Kingdom the National Disability Council is an independent statutory advisory council, providing advice to government. Membership is drawn from disability organisations and businesses.

Coherence and mainstreaming relates primarily to employment and social affairs. Health is also important in many countries, but environment, education and culture are exceptions. A global anti-discrimination approach has been adopted in Ireland, Finland and the United Kingdom. The anti-discrimination legislation introduced in Ireland and the United Kingdom explains the need for global monitoring and advice.

Most of the bodies in which people with disabilities participate have an advisory role. In some countries (e.g. Germany and Italy) social partners and NGOs work together, notably on employment and rehabilitation measures.

Mainstreaming is better served by the principle of 'sector responsibility'. This means that it is the responsibility of every sector of society to ensure that the services provided are accessible to people with disabilities. The principle is applied in many Member States (e.g. Denmark and Austria), but it does not ensure the participation of final users.

## The social partners<sup>17</sup>

In 1999 the social partners adopted a declaration on the employment of people with disabilities. UNICE/UEAPME, CEEP and ETUC noted that discrimination based on factors that were irrelevant to the task in question was socially unacceptable and economically inappropriate. The declaration presents rather general statements on equal opportunities for people with disabilities. This partly explains why the recommendations had little impact or follow-up in the Member States (European Foundation for the Improvement of Living and Working Conditions, EIROOnline).

In January 2003 the social partners adopted a new declaration 'Promoting equal opportunities and access to employment for people with disabilities'. Through this joint declaration they sought to make an effective and specific contribution to the European Year of People with Disabilities by giving impetus so that the occupational integration of people with disabilities is perceived as a shared interest by both companies and employees; and by acknowledging the broader dimension of the challenge, which calls for dialogue between the various stakeholders.

In Belgium the social partners have concluded an agreement that says an employer who is recruiting must treat applicants in a non-discriminatory way. The agreement covers all discriminatory grounds mentioned in Article 13 of the EU Treaty. The national Labour Council has laid down rules in accordance with the agreement. In Ireland national conventions refer to the specific problems of people with disabilities, while in Italy specific conventions have been established for workers with disabilities.

In France social partners at the company level established special agreements, aimed at ensuring respect for the quota obligation. In the Netherlands collective agreements at the company level aim to promote the reintegration of people with disabilities and to achieve an equitable employment share for them.

In some plants in Germany collective agreements oblige employers to give priority to taking on workers with disabilities, adapting workplaces and protecting their employment. A prospective approach has been adopted. Jobs that will be available in the near future are identified and steps taken to modify plant in order to ensure that a position can be made available to a disabled person (R. Harvey, 1998).

In Denmark and the United Kingdom employers have developed networks between companies in order to develop partnerships for the promotion of equal opportunities and social cohesion. In the UK the Trade Union Confederation considers that the Disability Discrimination Act ought to cover all SMEs and public services.

Action by trade unions has been successful in countries with legislation protecting disabled workers from dismissal. Work councils and trade unions have played an active role in defending the right not to be dismissed. In France and Germany they have been active in reaching agreements to further job retention policies within enterprises (P. Thornton, 1998).

It is important to note that the EU Directive 2000/78/EC of 27 November 2000 refers expressly to the contribution social partners may make to the implementation of the Directive. So it is interesting to assess existing and emerging new initiatives in this direction.

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<sup>17</sup> This part uses information drawn from the website of the European Foundation for the Improvement of Living and Working Conditions: EIROOnline.

Experience in the candidate countries shows that major restructuring has affected a relatively higher proportion of disabled workers, except where trade unions have used laws preventing unfair dismissal of workers with disabilities. Member States' experience in the management of disability and the elaboration of conventions at company level could be transferred to the future members of the EU.

The different actions show that dialogue in the workplace may make a significant contribution to the elimination of discrimination. Social corporate responsibility appears to be an alternative to compulsory measures.

### **The role of NGOs**

The involvement of representatives of people with disabilities in the implementation and follow-up of policies and actions that directly affect their lives contributes to the success of these measures. In fact they are in the best position to know the needs of the disabled and to assess the likely efficacy of proposed measures.

The involvement of representatives of disabled people may take place at different stages of the design, implementation, monitoring and assessment of relevant policies. Previous chapters looked at the participation of NGOs in structures aiming to guarantee coherence of national policies and on committees advising on accessibility issues. The involvement could be of an advisory or binding nature.

In Belgium the minister responsible for financial assistance to disabled people has to consult the Council on all Royal Decrees relating to their benefits. In Denmark the Danish Council of Organisations of Disabled People is usually consulted on questions of education, the labour market, benefits and insurance. The Council has a branch in each of the 15 counties in Denmark. Government ministries are only responsible for the development and implementation of legislation: local authorities are charged with the actual delivery of financial assistance and services to the disabled.

In Greece the Ministry of Health and Welfare takes into account the opinion of the Confederation of Disabled People on the conditions and procedures for subsidising disabled people's organisations. In applying the quota system at departmental level, the placement of people with a disability is supervised by a tripartite committee on which the Confederation is represented.

In France associations run most of the specialist services. The strategy of the Fund for the Occupational Integration of Disabled People was worked out by a large number of associations, authorities, employers and trade unions involved in implementing the Act of 10 July 1987. Integration programmes also bring together all partners responsible for occupational integration at Departmental level.

In Italy the 'Council of associations of people with disabilities and of their families' was established by departmental order. To achieve integration in schools, every provincial education department has to set up a working group including associations of disabled people, which are most representative at provincial level.

In Austria the Federal Disability Act created the Federal Advisory Committee on Disability to act in an advisory role on matters of policy for the disabled. The task of this committee is mainly to advise the Federal Ministry for Labour, Health and Social Affairs. It includes social partners and disabled people's associations. In Portugal, the National Council for the Rehabilitation and Integration of People with Disabilities advises the Minister.

In Finland about 220 out of 450 municipalities have Local Councils on Disability. The Advisory Board for Rehabilitation includes representatives of disabled people's organisations and advises the government on vocational rehabilitation and employment. In Sweden the State Secretary Group coordinates the government bodies dealing with issues relating to disabled people and functions as a forum for dialogue with organisations of people with disabilities.

There is a wide range of advisory bodies. However, organisations of disabled people maintain that their involvement is not substantial and that the committees are very often informed about policies when decisions have already been taken. The European Disability Forum believes that the participation of people with disabilities in the decision-making process is a priority area. The local approach is mainly developed in the Nordic countries and Italy.

### **Direct participation**

Participation of people with illnesses and disabilities may be through their representative NGOs or their trade unions (for disabled workers). But in certain cases direct participation appears to be the only relevant path. It seems to be especially relevant in the following two cases:

- assessment of disability/needs, and
- definition of individualised programmes.

The procedure for the provision of services is of particular interest as it is based on the evaluation of needs of the disabled person. Also, in the case of children, the participation of parents in the definition of special educational needs could avoid situations where a medical certificate alone determines the nature of education and the type of institution.

The definition of individualised programmes is often used in labour market schemes. The unilateral decision of an unemployment office that does not take into account the aspirations of the interested party has little chance of success.

### **Codes of good practice**

There are a huge variety of codes of good practice in the Member States published by public or private organisations. Information about their effectiveness is lacking, but in most cases they serve merely as documentary sources and lack any innovative qualities. In this section the main initiatives are reviewed, and these may be used as sources for further investigation.

The International Labour Office is elaborating a 'Code of practice on managing disability in the workplace' aiming to provide practical guidance (ILO, 2001). It treats the general duties of

employers and trade unions, strategies, recruitment, promotion, job retention, adjustments and the confidentiality of information.

The Foundation elaborated 'Making Workplaces Accessible: A CD-ROM Guide to the Integration of Disabled People into Industrial Workplaces' (European Foundation for the Improvement of Living and Working Conditions, 1996b).

Employers in the Member States have been very active and the following codes have been elaborated: a) The Confederation of British Industry published a guide on the Disability Discrimination Act (DDA) and good practices concerning equal opportunities; b) Employers in the Netherlands and Spain diffused information among their members on the adaptation of workplace, training, etc.; c) Belgian Flemish employers, in cooperation with the Flemish Fund for the Integration of Disabled People, elaborated a guide of good practice, based on the experience of 10 companies. At the European level, a joint action by social partners produced a booklet on good practices.

The experience of the United Kingdom seems interesting, because it treats the new anti-discrimination law. Two codes of good practice have been published by the Disability Rights Commission:

- 'Elimination of discrimination in the field of employment against disabled persons or persons who have had a disability': it describes and gives general guidance on the main provisions of the Disability Discrimination Act.
- 'Rights of Access to Goods, Facilities, Services and Premises'. This statutory code, agreed by Parliament, provides detailed advice on the way the law should work, together with practical examples and tips. Its status means it must be referred to for guidance in court when deciding on cases concerning the corresponding chapters of the Disability Discrimination Act.

The interest of these documents consists in the presentation of case studies, which are far more interesting than general information. In certain aspects they replicate American experience. Some examples could be useful:

- What does 'less favourable treatment' mean? An assistant in a small shop refuses to serve a disabled person, telling them that a nearby, larger shop can better meet their needs. While it is good practice to inform disabled people where they can find a service suited to their requirements, to refuse to serve them is likely to be unlawful.
- Do I have to make physical changes to my premises? A small petrol station decides that an assistant will on request help disabled people use the petrol pumps. It places a prominent notice at the pumps advertising this service and the hours it is available.

A similar code presenting the European anti-discrimination Directive could be developed, notably for countries without experience of similar instruments and for the candidate countries.

A thematic guide on mental health and work was published jointly by the World Health Organisation (WHO) and the International Labour Office (ILO). Good practice is presented on 'reasonable accommodation' for people with mental health problems, a problem rarely treated in other codes.

## **Anti-discrimination policy**

The Council Directive 2000/78/EC of 27 November 2000, establishing a general framework for equal treatment in employment and occupation, constitutes a major step in the development of anti-discrimination policy. The Directive prohibits any direct or indirect discrimination based on religion, or belief, disability, age or sexual orientation as regards employment and occupation.

Some Member States are expected to adapt existing anti-discrimination laws to the Directive, while others are expected to transpose it into new national legislation. The definition (beneficiaries), the obligations (accommodation), the areas covered (employment and occupation) and control mechanism are important elements in the Directive.

Different surveys report that the most common form of discrimination felt by people with disabilities relates to the recruitment process, but relatively few cases arrive in court. The most frequent cases brought to court relate to dismissals.

The EU Directive provides that 'in order to guarantee compliance with the principle of equal treatment in relation to persons with disabilities, reasonable accommodation shall be provided ... unless such measures would impose a disproportionate burden on the employer'. The principle of reasonable accommodation implicitly rejects the notion that organisations are neutral work environments in which the terms and conditions of employment are natural. It requires employers to examine the possibility that 'disability' is located in the work environment and to provide alternative job designs.

However, employers do not have to make accommodations that would change the essential functions of the job and, therefore, its likely productivity. Reasonable accommodation includes job restructuring, part-time work, reassignment to a vacant position, training tools, etc. Work schedule demands occur most frequently in reported cases.

The study of cases brought to court reveals that in some cases conflicts arise between the obligation of 'reasonable adjustment' and an employer's other obligations (e.g. health and safety). Different studies find that in the majority of cases reasonable accommodation amounts to less than €1,000; some even find that it is less than €500.

## **Independent living**

Recent policies favour living at home rather than in institutions. This raises the question of who is going to provide long-term care and assistance and whether services provided or paid for by public authorities are sufficient to meet the growing demand. There is a tendency for Member States to adopt a common approach. In general they take into account medical criteria and social criteria. Lack of autonomy in ordinary daily activities is the dominant aspect.

The increasing need for long-term care requires the revision of current policies (financing systems) and the development of insurance-type instruments in order to pay for expected future needs. The social partners may play an important role in the design and financing of such schemes.



Universal design standards have been introduced in some countries in order to support access to information and communication technologies. In the majority of Member States initiatives have been taken to improve the accessibility of public buildings and to adopt rules friendly to disabled people in new constructions. A prevention strategy has been adopted, grounded in sensitising and informing architects during their training.

Public procurement could be a tool for ensuring that disability is taken account of at the level of conception. Public procurement ought to ensure that people with disabilities are able to make use of the same goods and services as other members of society. Accessibility and functionality could be among the selection criteria.

An architectural interpretation of accessibility might not create the reasonable access that mobility-disabled users actually want. Accessibility ought to be interpreted in terms of the consumer's experience. Public policy ought to help service providers develop codes of reasonable access based on their own professional standards.

### **Social protection**

Comparing disability benefits across national legislations shows that some criteria are similar and that these elements could constitute the basis for European harmonisation. Recent policies have tried to reduce or stabilise expenditure on disability pensions. In some cases this has led to a reduction in beneficiaries but in general their number has remained stable in recent years.

The annual disability inflow rate is about 6%. It increases with age and is the same in most European countries. This shows that labour market indicators have a relatively small impact on disability application. Health issues appear to be the dominant ones.

The situation in the Netherlands and to a lesser extent in the United Kingdom requires special measures. For the remaining countries, substitutability between unemployment benefits and disability benefits among elderly workers seems small. In any case it does not seem to apply to the young disabled.

A review of different studies shows that policies aimed at increasing the labour participation of people with an illness or disability by reducing the level of benefits are likely to fail. Furthermore, such policies could harm those who are truly disabled. This probably explains why countries wanting to reduce disability applications focus on eligibility criteria, notably by imposing more stringent conditions or stressing medical criteria.

It is important to note that reducing the effect of chronic illness and disability on disabled people will not make them the same as the average non-disabled person. The probability of non-participation in work for disabled people will not be the same as the average for the non-disabled. This is because people with an illness or disability are more likely to be older and have less education than non-disabled persons, which makes them less likely to work.

## Employment

The definition of beneficiaries is generally wider than for disability pension schemes, but some important differences remain between countries over certain groups (e.g. drug addicts). Most countries share the following orientations:

- the dominant criterion for granting an employment subsidy or assistance is the presence of difficulties in obtaining or keeping a job;
- the desire to compensate for disadvantage and ensure equal opportunities.

These elements could constitute the basis for European harmonisation.

There is a large similarity between Member States over adopted measures. The main measures include:

- a) labour subsidies, granted either to the employee (increase of wage income) or the employer (reduction in labour costs);
- b) special schemes to provide work experience; and
- c) start-up grants to set up own business and self-employment.

The provision of personalised support constitutes an important orientation in most Member States. It includes grants for a tutor, job coach or a personal assistant in the enterprise. A regular evaluation of adopted measures is desirable.

The obligation to employ a minimum ratio of people with an illness or disability exists in ten Member States. Despite several criticisms levelled at the scheme, quota schemes remain the main visible, permanent policy in support of people with an illness or disability in the majority of Member States. According to available information quota schemes have some success in Germany and to a lesser extent in France and Austria. One major criticism concerns the quality of jobs offered.

It is desirable to study further whether companies should be invited to produce an annual report in which they indicate the number of people employed with a chronic illness or disability. This administrative obligation to report could be organised at a European level. Some kind of sanction could be imposed in case of non-reporting (e.g. exclusion from public procurement and refusal of general financial assistance).

Sheltered employment is open to people who, because of their disability, are unable to obtain or keep a normal job, whether supported or not. Sheltered workshops employ about 500,000 workers. There are large differences between countries. Numbers vary from 0.1% (Mediterranean countries) to 1% (Netherlands) of the total labour force. Critics argue that there is a low rate of movement from sheltered workshops to open employment and that management ought to establish bridges between the workshops and the open labour market.

Sheltered workshops ought to develop innovative management techniques that combine efficiency and social goals. They should also establish bridges that support the temporary placement of disabled workers in an open environment.

### **Reintegration at work**

There is a wide range of nominal measures in the Member States, aimed at reintegrating people who acquire an illness or a disability. Some of them are legally binding but in some cases there is no penalty in case of non-application, while in other cases the application is weak. Available studies reveal that huge differences in return-to-work rates exist between countries. It appears that active policies combined with compulsory legal instruments may explain the relatively high return rate to previous employers in some countries.

The involvement of social partners at the company level is of strategic importance. Identifying good practice could increase the possibilities for transfer/replication at a European level. In principle, reintegration into the same company ought to cover everyone without distinction as to the origin of a disability (work accident, home accident, etc.). In such cases public policy could help companies in their efforts to reintegrate disabled people into their previous jobs, through subsidies for technical aids, workplace adaptation, etc.

Work accidents and occupational diseases present a specific problem. Companies with bad accident records ought to pay fines or differentiated premiums. The fine or differentiated premium ought to reflect the cost that is not already borne by the company and is supported by the community (pensions, rehabilitation, etc.).

### **Education**

The European Commission (2001) notes that Member States are recognising the importance of integrating disabled children with special needs into the mainstream education system.

Special schools ought to be the exception and cater only for pupils with severe disabilities. The experience of turning these schools into resource centres for support services ought to be evaluated by other Member States. In fact ordinary schools often give the lack of specialised support for their disabled pupils as one important reason for inaction. Support services could include psychologists, counsellors, medical services, ergotherapy, physiotherapy, psychology, counsellors in pedagogy, etc.

All children ought to have access to ordinary schools with the appropriate support. Special education should be the exception. The integration policy ought to be based on a universal rights approach – one of children's rights. The inclusion of education in the areas covered by the anti-discrimination Directive provides a strong instrument that ensures equal access to ordinary education for all children. A transfer from an ordinary school to a special school due to lack of adequate services and accessibility ought to be considered as discrimination.

### **Evaluation**

There is a need for a more systematic evaluation of national policies, based on sound quantitative methods. Evaluation of global policies shows that public policy has a general, positive impact on the employment of people with moderate disabilities.

As regards individual measures, some studies indicate that general wage subsidies have a 'windfall effect' for employers and that the substitution effect is a dominant characteristic, while net job creation is marginal. The traditional criticism, that wage subsidies and other measures could lead to substitution effects, ought to be taken into account even in the case of a policy aiming to achieve an equitable redistribution of existing jobs. Substitutability is high between disabled people and poorly educated, unskilled workers, so such policies could simply replace one form of inequity by another form. On workplace adaptation, it is important to note that the take-up of subsidies is very low in certain countries.

OECD evaluations of policies on disadvantaged people show that successful training programmes ought to:

- a) have precise targets concerning participants,
- b) favour programmes with relatively small numbers, and
- c) include an important component of on-the-job training and establish strong links with local employers.

Precise definitions of the target group risk leading to stigmatisation. They discourage workers from participating and are interpreted by employers as meaning low productivity and a low level of attachment to the labour market. It should also be borne in mind that people with a chronic illness or disability do not make up a homogeneous group and large differences exist within sub-groups.

Comparisons of national policy indicate that there is a minimum level of expenditure under which a policy has no significant impact. In fact there is no relation between active policy and the employment of disabled people, under the threshold of 0.1% of GDP. This shows that adequate measures require a minimum level of resources. Actions that are limited in scope, uncoordinated and lacking coherence do not seem to be successful.

The target of 0.1% of GDP does not necessarily mean an increase in available resources. The first step is better coordination and coherence of available services.

### **Mainstreaming and coherence**

In many countries special structures aim to ensure the coherence of national actions. Often they favour participation of NGOs. But there is an important limitation. These structures focus on specific measures in support of people with disabilities, so they lack the mainstreaming approach. Mainstreaming the disability perspective into all relevant sectors of policy formulation requires taking into account the needs of disabled people when developing general policies. This approach requires action at an early stage, often in cooperation with those who will be affected by the proposed actions.

The opinion of disabled people's organisations should be requested for general measures, with the aim of identifying any adverse effects on people with disabilities and making the necessary adjustments. In this way people with disabilities could have equal access to mainstream services and programmes that serve the whole population.

### Participation

The social partners adopted a declaration on the employment of people with disabilities. They noted that discrimination based on factors that were irrelevant to the task in question was socially unacceptable and economically inappropriate. There is no reference to accommodation and workplace adaptation in their recommendations. The declaration makes rather general statements on equal opportunities for people with disabilities.

It is important to note that the EU Directive 2000/78/EC of 27 November 2000 refers expressly to the contribution social partners may make in the application of the Directive, through the conclusion of agreements laying down anti-discrimination rules.

The involvement of representatives of disabled people in the implementation and follow-up of policies and actions that affect their lives contributes to the success of these measures. They are in the best position to know the needs of people with disabilities and to assess the probable efficacy of the measures proposed. Their involvement may take place at different stages of the design, implementation, monitoring and assessment of relevant policies.

There is a wide range of advisory bodies in the Member States. However, disabled people's organisations consider that their involvement is not substantial, and that these bodies are very often informed about policies when decisions have already been taken. Direct participation appears to be of particular interest in the following areas:

- assessment of disability/needs, and
- definition of individualised programmes.

There is a huge variety of codes of good practice in the Member States published by public and private organisations but information about their effectiveness is lacking. However, in most cases they serve merely as documentary sources and lack any innovative qualities.

The codes reveal the social responsibility of employers and their desire to contribute to the eradication of discrimination and to the implementation of relevant legislation. Given that many Member States lack experience on this field, it might be interesting to elaborate a code of good practice on the European anti-discrimination Directive.

In this final chapter the main conclusions are summarised and some proposals for future action put forward. These concern a wide range of activities. Some are directly linked to the work of the Foundation. Others are policy recommendations about working and living conditions in a broad sense. It seems clear that effectiveness is dependent on the coordination and the cohesiveness of different policies. For example, measures promoting independent living in the community could have an impact on care policy and the role of the family. A policy of preventing illness and disability could require an improvement in working conditions and initiatives inside the company.

This shows that these interrelations have to be taken into account in order to favour the inclusion of different perspectives. All the proposals share and contribute to the implementation of a common objective: the inclusion of people with illness and disability.

## **Characteristics of people with illness or disability**

European surveys have greatly improved the collection of comparable statistics in the Member States. However, there is one field that remains still unexploited: the nature of illness and disability and the needs for aids and assistance.

## **Socio-economic determinants**

The analysis of the socio-economic characteristics of people with illness and disability reveals that poorly educated people, poor, unskilled workers, and the unemployed constitute high risk groups. Both absolute and relative factors seem to be important.

So there is a need to monitor the health conditions of these disadvantaged groups. Trends in socio-economic inequalities in morbidity and disability ought to be identified and if possible corrected at an early stage. Also it is interesting to monitor evolution – notably whether inequality (in physical and mental health) increases or decreases.

## **Barriers and autonomy**

Physical and architectural barriers continue to create obstacles for participation in social and working activities. Governments ought to guarantee the application of a certain number of rules. For example, the principle of functionality and accessibility ought to permeate all public construction projects. A minimum set of guidelines should be applied to private projects open to the general public. To this end the disability perspective should be taken into account whenever public support is granted to finance any action.

An architectural interpretation of accessibility could not create the reasonable access that mobility-disabled users actually want. Accessibility ought to be interpreted in terms of consumer experience. Public policy ought to help service providers develop codes of reasonable access based on their own professional standards.

Rules on standardisation, public procurement, provision of services, etc. could be promoted by the state. They ought to aim to enable people with disabilities to use the same goods and services as everybody else. Initiatives taken by some countries ought to be evaluated and replicated in others.

Public procurement could be a tool for including the disability perspective at the level of conception. It ought to ensure that people with disabilities are able to make use of the same goods and services as other members of society. Accessibility and functionality ought to be respected and included in selection criteria. Anti-discrimination clauses could be included in public procurement. Public grants and subsidies could be used as instruments to favour a 'universal design' approach. They could be given to organisations that respect a minimum number of accessibility criteria.

Rules favouring accessibility should not be seen as a cost, but as an investment that reduces the need for subsequent help and makes it easier for people to manage their own lives. Both these elements reduce the number of services that have to be provided and so bring long-term benefits to society.

Legal and administrative barriers limit the freedom of some groups of people with an illness or disability. The rights of those with mental retardation and mental illness ought to be monitored closely, and efforts should be made to increase their control over their lives.

Living in the community and providing the necessary help to carers should be promoted. As most carers are women, public policy ought to favour a better distribution of tasks between men and women through different incentives (days off, working part-time, etc.).

### **Segregation**

Special education in closed institutions further isolates children from their families and the rest of society. The mentally disabled are the most segregated. Separation in closed institutions remains the rule, with few exceptions.

Children are a priority. Eliminating discrimination at an early age has strategic implications for the rest of their lives. In the same way, it is important to analyse the situation of children with mental problems in closed institutions.

### **Mental health**

The number of people with mental health problems is increasing. There is a need to monitor mental health problems like depression, stress and drug abuse. A policy of prevention requires an understanding of the socio-economic characteristics of these groups. Different studies find that those with mental problems have the most problems in comparison with other types of illness or disability. So it is especially important to monitor their mental health problems. In the EU twice as many women as men are prone to mental problems, and it is important to identify the reasons and devise an appropriate policy response.

### **Working conditions**

The quality of work is a major determinant of health. The participation of social partners here may be decisive in the success of future action. The following approaches appear to be important:

- monitoring the working and health conditions of vulnerable groups (temporary contracts, etc.);
- considering the feasibility of imposing fines or differentiated premiums on companies with bad accident records, and making them share the cost of rehabilitation;
- focusing on new forms of occupational disease like stress and depression.

The imposition of fines or differentiated premiums on companies with bad accident records should be introduced. The fine or differentiated premium ought to reflect the cost that is not borne by the company but is shouldered by the community (pensions, rehabilitation services, etc.). In this way, the unfair competitive advantage of companies with bad accident records can be eradicated. The development of such schemes (e.g. fines) should be governed by the principle that the company ought to bear the total cost, and by fair competition.

### **Labour market issues**

The labour market participation of people with an illness or disability is relatively low. The general situation in the labour market and pure health considerations seem to be the dominant factors, but specific factors may also play a significant role.

Analysis of the position in the Member States shows that in some cases there are strong disincentives to participate in the labour market as the result of the tax system. The impossibility of acquiring a disability pension and earning income from work appears to be a significant disincentive.

A European policy aimed at increasing the labour participation of people with disabilities and reducing large differences between Member States ought to have these targets:

- to reduce the relative disadvantage of people with disabilities in those countries where the employment ratio of disabled to non-disabled people is low;
- to set a target that takes into account severe and moderate disability;
- to diversify the nature of jobs in countries that have already attained the target, as this could further improve the employment and the activity rate of people with disabilities.

Despite legal protection, people with an illness or disability earn much lower wages than the average for the population. So it would be interesting to monitor wage differentials between the disabled and the non-disabled, and to identify the source of the gap. Discrimination or lack of qualifications could be important factors, but the policy requirements are very different in each case.

### **Anti-discrimination**

The European Anti-discrimination Directive is an important step. For many countries this is a new instrument and its application could be difficult. So it will be interesting to monitor the progress of implementation and to support the exchange of good practices. Reasonable accommodation is an important dimension of the new Directive. What does it imply for companies? What does it mean



for people with mental health problems and what are the consequences for those with mental retardation? These questions are still at the centre of the debate. Successful application of the Directive needs the provision of help to employers. To this end a European guide could be useful.

### **Independent living**

The ageing of the population and the subsequent increase in the need for long-term care requires the revision of current policies (financing systems) and the development of insurance-type instruments in order to pay for likely future needs. Social partners could play an important role in the design and financing of such schemes. The provision of home help and the problems of informal carers should also be taken into account.

### **Social protection**

Analysis of national policies shows that those aimed at increasing the labour participation of people with an illness or disability by reducing the level of benefits are likely to fail. Furthermore, such policies could harm those who are truly disabled and ought, in any case, to focus on older workers.

Policy should concentrate on increasing the likelihood of obtaining job offers, on improving the accessibility of the working environment, and on the provision of technical aids at work – factors that seem to be much more powerful in bringing about labour reintegration.

The situation in the Netherlands, and to a lesser extent in the United Kingdom, requires special measures. For the remaining countries substitutability between unemployment benefits and disability benefits among elderly workers seems slight. In any case it does not affect the young disabled.

Measures to restrict the accessibility of disability benefits ought to avoid the exclusion of the young disabled. The disability inflow rate of about 6% for most European countries shows that labour market factors have a low impact on disability application. Health issues appear to be the dominant ones. There is a wide agreement that:

- declining overall health implies a lower probability of returning to work;
- better education is associated with a higher probability of returning to work;
- work experience is associated with a higher probability of returning to work.

Consequently public policy ought to focus on these issues, by providing training and work experience to young, inactive or unemployed people with an illness or disability.

### **Employment**

The definition of beneficiaries of employment measures varies between the Member States but there are common elements that could form the basis for European harmonisation. Visibility and the monitoring of employment measures would be enhanced if companies were to show in an

annual report (social report/balance sheet) the number of people with a chronic illness or disability employed by them.

This administrative obligation to report could be organised at a European level. Some kind of sanction could be imposed in case of non-reporting (e.g. exclusion from public procurement). Similar reports ought to be published by the public sector, to avoid less favourable treatment of private companies.

### **Reintegration**

Available studies reveal that large differences in return-to-work rates exist between countries. It appears that active policies in combination with compulsory legal instruments may explain the relatively high return rate to previous employers in certain countries. In order to improve the situation, those efforts made by companies to re-integrate workers should be looked at so as to identify reasons for non-compliance and make proposals, taking into account the social responsibility of business.

### **Education**

All children should have access to ordinary schools with appropriate support. Special education ought to be the exception. The mainstreaming policy ought to be based on a universal rights approach – that of children's rights. Education could be a possible area for an anti-discrimination Directive. A transfer from an ordinary school to a special school due to lack of adequate services and accessibility should be considered discrimination.

### **Evaluation**

There is a need for a more systematic evaluation of national policies based on sound quantitative methods. National policies ought to integrate people with disabilities into general schemes, following the principle of mainstreaming. When necessary they should specify complementary incentives for people with a chronic illness or disability and define precisely the target group of beneficiaries, without creating a stigma. It should be noted that people with a chronic illness or disability do not make up a homogeneous group.

National policies could follow a job creation target or a redistribution of existing jobs in order to reduce substantial inequalities. In the case of distributional equity, proposed measures ought to avoid substituting one disadvantaged group for another. National policies ought to guarantee minimum resources to finance a significant level of active labour market measures. Limited measures seem to be unsuccessful. This minimum level could be 0.1% of Gross Domestic Product.

### **Mainstreaming**

Mainstreaming and coherence concern all aspects of social life, so the relevant structures ought to cover different areas. The opinion of disabled people's organisations should be requested when

devising general measures, in order to identify any adverse effects on the disabled and to make the necessary adjustments. These structures, whenever possible, should also adopt the horizontal approach set out in Article 13 of the Treaty and in the anti-discrimination Directive.

### **Social partners**

The role of social partners in implementing the anti-discrimination Directive could have a significant effect on employment and occupation. So it would be interesting to make an inventory and assessment of initiatives in this direction taken by social partners in the Member States.

### **NGOs**

NGOs may bring about significant improvements in the shaping of policies. So it is worth strengthening the involvement of disabled people's organisations, both at national and local level, in the provision of services and the shaping of programmes.

### **Codes**

European information and awareness measures could include the drafting of a code of good practice on the European anti-discrimination Directive. This code could focus on the obligations of employers and concepts such as 'reasonable accommodation'.

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# Glossary

The glossary presents the definitions of key concepts relating to chronic illness and disability, which are in use in the Member States and international organisations. For each term, the source of the definition is given. The aim of such a glossary is twofold: it attempts to clarify the terms of the debate, and also to show the relationship between the concept and the policy. The evolution of the meaning or wording of certain terms is indicative of a policy change. Furthermore, new approaches have introduced new concepts into the debate, which merit clarification. The glossary is not exhaustive, being restricted to those terms which are related to the main topics covered in the report.

## **Accommodation or adjustment**

Adaptation of a job, including adjustment and modification of machinery and equipment and/or modification of the job content, working time and work organisation, and the adaptation of the work environment to provide access to the place of work and to facilitate the employment of individuals with disabilities (ILO, 2001). See also 'Reasonable accommodation'.

## **Activities of daily living**

*Activities of daily living (ADL)*

They include self-care activities, such as bathing, dressing and feeding oneself.

*Instrumental activities of daily living (IADL)*

They include domestic activities such as cooking, shopping and house keeping.

*Katz index*

This index has six items: washing, dressing, transfer, going to the toilet, continence and eating. For each item, four cases are given. In the case of washing, a person able to wash without assistance receives a score of zero points. A person needing assistance in washing the lower part of the body receives one (1) point, etc. A fully self-sufficient person has a total score of zero (0).

- Full self-sufficient person: Katz index = 0,
- Moderately care-dependent: Katz index = 1 or 2,
- Highly care-dependent: Katz index = 3 or 4,
- Very highly-care dependent: Katz index = 5 or 6.

## **Advocacy**

A combination of individual and social actions designed to raise awareness and to gain political commitment, policy support and social acceptance (WHO: Atlas, 2001).

## **Article 13**

Article 13 of the Treaty provides the Community with specific powers to take action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.

## **Assessment**

*Medical assessment*

Assessment of abilities made by doctors specialising in rehabilitation.

### *Self-assessment*

Question asking interviewees to rate on a scale their overall health or ability to carry out a certain number of activities. The scale often used is from 'excellent' to 'poor'. Problems could arise if the interviewees do not use the same frame of reference. The assessment could be culturally biased and the results not comparable between countries. Age and gender could also have asymmetric impacts on the results.

### *Social and occupational assessment*

Assessment that takes into account social factors (education, family status, work experience, etc.). It is often used with medical assessment to assess work capacity reduction.

### **Autonomy**

The ability of a person to make decisions for themselves and implement these.

### **Care**

#### *Carer*

A person who supports a dependent person. Often used to designate the non-professional, benevolent provider of care and assistance.

#### *Community-based care*

Any type of care, supervision and rehabilitation outside the hospital by health and social workers based in the community (WHO: Atlas, 2001). Community care is associated with the provision of services and care at home rather than in an institution.

#### *Institutional care*

Care in institutional settings (notably, rest and nursing homes), also called residential care. Currently, priority is given in a certain number of countries (e.g. Nordic countries) to a return to the community: 'disinstitutionalisation'.

### **Council of Europe Recommendation No R(92) 6**

The Recommendation No R(92) 6 concerning a coherent policy for disabled people was adopted on 9 April 1992. It aims to a) prevent or eliminate disablement, b) guarantee full and active participation in community life, and c) help people with disabilities to lead independent lives, according to their own wishes.

### **Dependency**

Dependency is defined as the need for a third party in the activities of daily living. It measures the extent to which a person needs help from others to maintain a normal life. This has to be distinguished from the population dependency ratio: the ratio of retired people and children under 16 years of age to the working-age population. Sometimes the denominator uses the economically active population.

**Disability**

The International Classification of Impairments, Disabilities and Handicaps (ICIDH) published by the World Health Organisation (WHO) distinguishes: impairment, disability and handicap (WHO, 1980).

Impairment	Disability
Any loss or abnormality of psychological, physiological or anatomical structure or functions.	Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner of or within the range considered normal for a human being.
<ol style="list-style-type: none"> <li>1. Intellectual impairments</li> <li>2. Other psychological impairments</li> <li>3. Language impairments</li> <li>4. Aural impairments</li> <li>5. Ocular impairments</li> <li>6. Visceral impairments</li> <li>7. Skeletal impairments</li> <li>8. Disfiguring impairments</li> <li>9. Generalised, sensory, and other impairments</li> </ol>	<ol style="list-style-type: none"> <li>1. Behaviour disabilities</li> <li>2. Communication disabilities</li> <li>3. Personal care disabilities</li> <li>4. Locomotor disabilities</li> <li>5. Body disposition disabilities</li> <li>6. Dexterity disabilities</li> <li>7. Situational disabilities</li> <li>8. Particular skill disabilities</li> <li>9. Other activity restrictions</li> </ol>

**Handicap**

A disadvantage, for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for the individual.

The term 'handicap' refers to the relation between people and their environment. It involves a limitation of scope to participate in community life on an equal footing with others.

**Disability Adjusted Life Years (DALYs)**

Quality adjusted life years (QALYs) is a summary measure of health gain that combines life expectancy and quality of life. A year of full health is assigned a weight of one, and a state that is considered equivalent to death is assigned a value of zero. Health states that lie between these two limits will be given a weight that lies between zero and one. For example, a given status of health (e.g. living with a chronic disease) may be assigned a weight of 0.75. Living for 20 years with a chronic disease would then be considered equivalent to 15 QALYs ( $20 \times 0.75 = 15$ ). A policy preventing chronic disease would lead to a health gain of five QALYs (A. Shiell et al, 2002). Disability is one possible health state and the measure is called DALY.

**Disability Free Life Expectancy (DFLE)**

Number of years of projected life expectancy that will be spent free of disability (A. Bowling and S. Ebrahim, 2001). Disability free life expectancy is important because it indicates not only the increase in the number of years but also the quality of life during these additional years.

**Discrimination**

The EU Directive 2000/78/EC of 27 November 2000, establishing a general framework for equal treatment in employment and occupation, lays down a general framework for combating discrimination on the grounds of religion or belief, disability, age or sexual orientation as regards employment and occupation. Member States have to adopt the laws, regulations and administrative provisions necessary to comply with this Directive by 2 December 2003 at the latest. Gender discrimination is tackled in a specific Directive.



### *Direct discrimination*

Direct discrimination occurs when one person is treated less favourably than another is, has been or would be treated in a comparable situation, on any of the grounds noted above.

### *Indirect discrimination*

Indirect discrimination occurs where an apparently neutral provision, criterion or practice would put people having a particular religion or belief, a particular disability, a particular age, or a particular sexual orientation at a disadvantage compared with others.

### *Statistical discrimination*

Statistical discrimination occurs when someone associates a characteristic with the probability of success and uses this differentiation as a rule of thumb. Treating two groups differently may also be the response of decision-makers to uncertainty about people's characteristics. For example, an employer could associate disability with low productivity and so use this discrimination as a rule of thumb during hiring and wage determination. Uncertainty and employer risk aversion, in this case, will produce different mean wages even if the average productivity of the two groups (disabled and non-disabled) is equal.

The EU Directive notes that indirect discrimination can be established by any means including on the basis of statistical evidence.

### *Economic discrimination*

Economic discrimination occurs when groups with equal average initial endowments of productive ability do not receive equal average compensation (S. J. Lundberg and R. Startz, 1983).

The ILO defines discrimination as any distinction, exclusion or preference based on certain grounds that nullifies or impairs equality of opportunity or treatment in employment or occupation (ILO, 2001).

## **EDF (European Disability Forum)**

The EDF is a European umbrella organisation representing more than 37 million disabled people in Europe. Its mission is to ensure disabled citizens' full access to fundamental and human rights through their active involvement in policy development and implementation in the European Union.

## **Equal opportunity**

Equal chance to achieve a certain outcome (on the same footing as other people) through the elimination of eventual barriers, the provision of means to overcome them or the delivery of compensatory measures.

The Council, in its resolution of 17 June 1999, on equal employment opportunities for people with disabilities, affirms that equal employment opportunities for people with disabilities will be enhanced if specific attention is given to recruitment and retention of employees, promotion, training, life-long learning and development, and protection against unfair dismissal, and if appropriate support is provided in such areas as:

- workplace accommodation, such as technical equipment – including access to new information and communication technologies;
- access to the place of work;
- qualifications and skills required at work; and
- access to vocational guidance and placement services.

### **Exclusion**

Following the introduction under Articles 136 and 137 EC by the Amsterdam Treaty of the fight against social exclusion among the social policy provisions, the European Council of Lisbon in March 2000 recognised that the extent of poverty and social exclusion was unacceptable. Building a more inclusive European Union was thus considered an essential element in achieving the Union's ten-year strategic goal of sustained economic growth, more and better jobs and greater social cohesion. The Lisbon Council agreed to adopt an Open Method of Coordination in order to make a decisive impact on the eradication of poverty and social exclusion by 2010.

According to Article 137 of the Treaty, the Council may adopt measures designed to encourage cooperation between Member States in order to combat social exclusion. Also, it provides for the fostering of integration of people excluded from the labour market, by adopting minimum requirements at Community level.

Social exclusion implies the inability of individuals to participate in the basic political, economic and social functioning of the society in which they live (Lenoir cited in Tsakloglou et al, 2001).

Social exclusion is characterised by five key factors (J. Room cited in Tsakloglou et al, 2001):

- it is multidimensional: it includes not only income but a wide range of indicators of living standards;
- it is dynamic: specific factors determine entry or exit from it;
- it has a neighbourhood dimension: deprivation is caused not only by lack of personal resources but also by unsatisfactory community resources;
- it is relational: it implies inadequate social participation and lack of power;
- it implies a major discontinuity in the relationship of the individual with the rest of the society.

### **Handicap**

A disadvantage for a given individual resulting from impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for the individual. The term 'handicap' refers to the relationship between people and their environment. It involves a limitation of scope to participate in community life on an equal footing with others.

### **Health**

Health, as defined in the WHO constitution, is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO: Atlas, 2001). The WHO

distinguishes: physical health, mental health and social health. The EU Treaty stipulates that the objective of ensuring a high level of human health protection must be incorporated in the definition and implementation of all Community policies and activities.

### **Health status**

Self-perceived physical, psychological and social health. A question on self-perceived status is often used in surveys and censuses.

Health status by income level: ratio of the proportions in the bottom and top quintile groups (by equivalised income) of the population aged 16 and over who classify themselves as in a bad or very bad state of health according to the WHO definition (EU Social protection committee, 2001).

### **Health impact assessment**

This is the estimation of the effects of a specified action on the health of a population. Health impact assessment is used to assess policies or programmes. These may or may not have health as their primary objective. It is often used to identify how the proposed actions will affect specific determinants of health (M. Douglas and A. Scott-Samuel, 2001).

### **Illness and disease**

Chronic illness comprises all impairments or deviations from the norm that have one or more of the following characteristics: are permanent; leave residual disability; are caused by non-reversible pathological alterations; require special training of the patient for rehabilitation; may be expected to require a long period of supervision, observation or care. A duration of minimum six months is required (A. de Bruin and H. S. J. Picavet, 1992).

There is an extensive debate on the meaning of disease, illness or disorder, especially whether these terms are scientific or biomedical, or whether they are socio-political terms that necessarily involve value judgements. This is important for the definition of cases such as drug addiction, alcoholism and obesity.

‘The socio-political definition is that a condition is regarded as a disease if it is agreed to be undesirable (an explicit value judgement) and if it seems on balance that physicians (or health professionals in general) and their technologies are more likely to be able to deal with it effectively than any of the potential alternatives, such as the criminal justice system (treating it as crime), the church (treating it as sin) or social work (treating it as a social problem)’ (R. E. Kendell, 2002).

The biomedical criterion for identifying disease is the biological disadvantage, notably in terms of fertility and life expectancy (R. E. Kendell, 2002).

ICD-10 uses impairments (as signs and symptoms) as parts of the constellation that forms a disease, or sometimes as reasons for contact with health services (WHO, 2001).

Alcoholism is treated in general as a disease. Medical treatment is accepted as being the solution. Obesity is not accepted as a genuine illness but could be considered so, if medical treatments become effective. For drug addiction, in certain cases ‘substance abuse’ or ‘problematic use of substances’ is mentioned (WHO: Atlas, 2001)

**Inclusion**

Inclusion is the ability of individuals to participate fully in the political, economic, social and cultural functioning of the society in which they live. It implies equal opportunities, empowerment and active citizenship in mainstream society. See also 'exclusion'.

**ILO Convention 159 and Recommendation 168**

Convention No 159 and Recommendation No 168 concerning vocational rehabilitation and employment of disabled people was adopted on 20 June 1983 (ILO, 1998).

The Convention includes:

- Part I: defines the term disabled and the concept of vocational rehabilitation;
- Part II: lays down the principles of a national policy on vocational rehabilitation and employment of disabled people (equality of opportunity and participation), and provides for the consultation of social partners;
- Part III: deals with vocational rehabilitation and employment services.

According to the Convention 'the term disabled person means an individual whose prospects of securing, retaining and advancing in suitable employment are substantially reduced as a result of a duly recognised physical or mental impairment'. Several Member States use this definition in the framework of employment and rehabilitation policies.

The Convention has been adopted by the majority of Member States; the exceptions are Austria, Belgium, Italy, Luxembourg, Portugal and the United Kingdom (European Commission, 1999).

The Recommendation lists measures that enable these people to be integrated into ordinary working life. It recommends the participation of disabled people's organisations and social partners.

**Independent living**

Independent living is the concept of empowering disabled people to control their own lives as far as possible and to have the freedom to participate fully in the life of the community (UK Department of Health, 2000). Support for independent living includes personal assistance, information, housing, education, and access to the environment and the political arena.

Independent living means that people with disabilities have the choices and control in their everyday lives that non-disabled people take for granted. This means growing up in their families, going to ordinary schools, using the same buses as other people, starting families, etc. just like everybody else (A. Ratzka, 2002).

**International Classification of Diseases (Tenth Revision)**

ICD-10 is a classification of health conditions (diseases, disorders, injuries, etc.). Functioning and disability associated with health conditions are classified in the International Classification of Functioning, Disability and Health (ICF). Consequently ICD-10 and ICF are complementary.

**International Classification of Functioning, Disability and Health (ICF)**

ICF constitutes a revision of the International Classification of Impairments, Disabilities and Handicaps (ICIDH). ICF was endorsed for international use by the Fifty-fourth World Health Assembly on 22 May 2001 (WHO, 2001). It defines components of health and some health-related components of well-being (such as education and labour). It presents two basic lists:

- Part 1. Functioning and disability
  - a) Body functions and structures.
  - b) Activities and participation.
- Part 2. Contextual factors
  - a) Environmental factors.
  - b) Personal factors.

The terms of Part 1 replace the formerly used terms ‘impairment’, ‘disability’ and ‘handicap’. ICF also lists environmental factors that interact with all other constructs.

<p><b>Body functions</b></p> <p>Body functions are the physiological functions of body systems (including psychological functions),</p> <ol style="list-style-type: none"> <li>1. Mental functions</li> <li>2. Sensory functions and pain</li> <li>3. Voice and speech functions</li> <li>4. Functions of the cardiovascular, haematological, immunological and respiratory systems</li> <li>5. Functions of the digestive, metabolic and endocrine systems</li> <li>6. Genito-urinary and reproductive functions</li> <li>7. Functions of the skin and related structures</li> </ol>	<p><b>Body structures</b></p> <p>Body structures are anatomical parts of the body such as organs, limbs and their components.</p> <ol style="list-style-type: none"> <li>1. Structures of the nervous system</li> <li>2. The eye, ear and related structures</li> <li>3. Structures involved in voice and speech</li> <li>4. Structures of the cardiovascular, immunological and respiratory systems</li> <li>5. Structures related to the genito-urinary and reproductive systems</li> <li>6. Structures related to movement</li> <li>7. Skin and related structures</li> </ol>
<p><b>Activities and participation</b></p> <p>Activity is the execution of a task or action by an individual. Participation is involvement in a life situation.</p> <ol style="list-style-type: none"> <li>1. Learning and applying knowledge</li> <li>2. General tasks and demands</li> <li>3. Communication</li> <li>4. Mobility</li> <li>5. Self-care</li> <li>6. Domestic life</li> <li>7. Interpersonal interactions and relationships</li> <li>8. Major life areas</li> <li>9. Community, social and civic life</li> </ol>	<p><b>Environmental factors</b></p> <p>Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.</p> <ol style="list-style-type: none"> <li>1. Products and technology</li> <li>2. Natural environment and human-made changes to the environment</li> <li>3. Support and relationships</li> <li>4. Attitudes</li> <li>5. Services, systems and policies</li> </ol>

Impairments are problems in body functions or structure such as significant deviation or loss. Activity limitations are difficulties an individual may experience in life situations.

**Intellectual disability**

This disability is defined by people’s capacity to learn and by what they can or cannot do for themselves (ILO, 2000). The term mental retardation is also used. The preferred term is ‘learning disability’.

**Job adaptation**

The adaptation or redesign of tools, machines, workstations and the work environment to an individual's needs. It may also include adjustments in work organisation, work schedules, sequences of work and in breaking down work tasks to their basic elements (ILO, 2001).

**Limiting long-standing illness**

Illness with a minimum duration (six or twelve months) that leads to activity limitations.

Question frequently used in surveys and censuses in an effort to estimate the prevalence of disability. Addition of the words 'including problems due to old age' increases the prevalence markedly (A. Bowling and S. Ebrahim; 2001).

Most of the national health surveys have a similar question. For example the Belgian survey contains a module that gauges the presence of long-term functional limitations due to chronic conditions. The questions relate to the ability to perform the following tasks: vigorous activities (e.g. running), moderate activities (e.g. moving a table), lifting or carrying groceries, climbing, bending, walking more than one kilometre, bathing, showering or dressing yourself. Additional questions relate to the following functions: locomotion, washing, eating, using the toilet, incontinence, hearing, sight, chewing hard foods (J. Breda and J. Geerts, 2001).

**Mainstreaming**

The Council, in its resolution of 17 June 1999 on equal employment opportunities for people with disabilities, calls upon the Commission to work together with the Member States, in particular within the framework of the European employment guidelines and in accordance with the mainstreaming principle.

Disability mainstreaming: all ministries are responsible for equality in their respective policy fields. This contrasts with previous policies, which were focused primarily on special measures for eliminating disability-related barriers to integration. The mainstreaming approach does not exclude specific measures.

Mainstream education aims to enable children with disabilities to attend mainstream schools. This could require medical services, adapted classes, assistance to the teacher, accessibility and transport, adapted teaching methods and materials, etc.

**Mental health**

Mental health is the successful performance of mental functions, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity specific to the individual's culture (ILO, 2000). Mental illness refers collectively to all diagnosable mental health problems that become clinical – that is where a degree of professional intervention and treatment is required (ILO, 2000). Consequently mental health problems or difficulties include mental illness and less serious cases.

Mental disorders are health conditions characterised by alterations in thinking, mood or behaviour associated with distress and/or impaired functioning (ILO, 2000). Depression is an example of a

mental disorder. The Diagnostic and Statistical Manual (DSM-IV) of the American Psychiatric Association stipulates that 'neither deviant behaviour nor conflicts that are primarily between the individual and society are mental disorders unless the deviance or conflict is a symptom of a dysfunction in the individual'.

Council resolution of 18 November 1999 on the promotion of mental health (Council, 2000):

- considers that mental health contributes significantly to quality of life, to social inclusion and to full social and economic participation;
- underlines that mental problems and illnesses are common, cause human suffering and disability, increase mortality, and have negative implications for national economies;
- underlines that the problems of mental health are often linked to unemployment, among other factors, social marginalisation and exclusion, homelessness and drug and alcohol abuse;
- considers that there is a need to enhance the value and visibility of mental health;
- invites the Commission to analyse, in particular, the impact of Community activities on mental health, for example in the fields of education, youth policy, social affairs and employment.

### **National Action Plan Employment**

Following the Amsterdam summit and the Luxembourg jobs summit, all Member States submitted National Action Plans for Employment (NAP). They described the national measures aimed at attaining the objectives of the Employment Policy Guidelines set by the Council. The Council, in its resolution of 17 June 1999 on equal employment opportunities for people with disabilities, underlined that the national action plans for employment provided a comprehensive platform within which policies aimed at integrating people with disabilities into the labour market should be strengthened.

### **National Action Plans Inclusion**

All Member States submit their National Action Plans against poverty and social inclusion (NAPs/incl) periodically in response to the common objectives on poverty and social exclusion agreed by the EU at Nice in December 2000. In these plans each Member State presents its priorities and efforts for the coming two years to promote social inclusion and combat poverty and social exclusion. The current round of National Action Plans is due to be completed in 2003.

### **Positive action**

The EU Directive 2000/78/EC of 27 November 2000, establishing a general framework for equal treatment in employment and occupation, states that 'with a view to ensuring full equality in practice, the principle of equal treatment shall not prevent any Member State from maintaining or adopting specific measures to prevent or compensate for disadvantage linked to religion or belief, disability, age or sexual orientation'. Positive action aims to prevent or compensate the disadvantage.

### **Prevention**

Prevention includes action taken as early as possible in the individual, medical, occupational and

social spheres as well as the improvement of surroundings (Council of Europe, 1992):

- to prevent an impairment from arising or worsening,
- to reduce as far as possible the degree of disability for a given impairment,
- to reduce any social disadvantage arising from a given disability.

### **Quota**

A measure obliging employers (in the private and/or public sector) to hire people with disabilities, as a specified percentage of their workforce.

### **Reasonable accommodation**

The EU Directive 2000/78/EC of 27 November 2000, establishing a general framework for equal treatment in employment and occupation, stipulates that employers have to provide 'reasonable accommodation'. 'This means that employers shall take appropriate measures, where needed in a particular case, to enable a person with a disability to have access to, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on the employer'.

### **Rehabilitation**

A process aimed at enabling people with disabilities to regain and maintain their optimal physical, sensory, intellectual, psychiatric, and/or social functional levels, by providing them with tools to change their lives towards a higher level of independence (ILO, 2000). It aims to further the autonomy of people with disabilities as individuals and to ensure their economic independence and full integration into society (Council of Europe, 1992).

Rehabilitation may take different forms:

- care given to people in the form of knowledge and skills to help them achieve their optimum level of social and psychological functioning (WHO: Atlas, 2001);
- vocational (training and) rehabilitation aiming to help people with disabilities to obtain or retain employment, to advance in their career and thereby to facilitate their integration or reintegration into society (ILO, see Convention 159 and Recommendation 168);
- medical rehabilitation comprising a combination of different forms of treatment designed to lessen the consequences of the injury, disease or infirmity and to restore the physical and mental functions; this is the main instrument used by the Member States.

### **Sheltered employment**

Employment open to people who, because of their disability, are unable to obtain or keep a normal job, whether supported or not.

Sheltered workshops are productive units that provide work to people with disabilities and prepare them for a job in the ordinary labour market. They provide people with disabilities with the necessary help. Sheltered work sections can be found within ordinary firms. Work centres receive people who cannot work in sheltered workshops or in an ordinary working environment, but who are nonetheless able, thanks to medical and social support, to carry out a remunerative



professional activity. Therapeutic centres may provide a valuable activity from a therapeutic perspective.

### **Social handicap**

Barriers to participation, autonomy and independent living imposed by society. Architectural and transport barriers are generally recognised but legal barriers (for example, the inability of people with an intellectual retardation to manage their budgets or limited access to certain jobs) are still in use in some countries.

### **Social health**

Quality of the interaction between individuals and their social environment (WHO in F. Louckx et al, 2001). Often it indicates a lack of social networks.

### **Special education**

Children who cannot attend an ordinary school, due to the gravity of their disability, receive tuition in special centres. These centres are equipped with collective and individual support and staffed by teachers with special teaching qualifications. In a certain number of cases they maintain links and cooperate with mainstream schools.

### **Stigma**

A mark of shame, disgrace, or disapproval, which results in an individual being shunned or rejected by others (ILO, 2000).

Stigma-adjusted effective benefit is the sum of expected benefits minus the cost this participation could induce (e.g. lower expected wage due to stigmatisation)

### **Technical aids**

Appliances designed to compensate for those functions which, for various reasons, can no longer be performed or are performed in an abnormal way because of physical or sensory damage, including low vision aids, adapted telephones, translators, etc. (Council of Europe, 1992).

### **UN standard rules**

The standard rules on the equalisation of opportunities for people with disabilities were adopted in a United Nations General Assembly resolution on 20 December 1993. Although not a legally binding instrument, the standard rules represent a strong moral and political commitment by governments to take action in 22 areas, grouped in three chapters:

- I. Preconditions for equal participation  
Rule 1: Awareness-raising; 2: Medical care; 3: Rehabilitation; 4: Support services.
- II. Target areas for equal participation  
Rule 5: Accessibility; 6: Education; 7: Employment; 8: Income maintenance and social security; 9: Family life and personal integrity; 10: Culture; 11: Recreation and sports; 12: Religion.
- III. Implementation measures

Rule 13: Information and research; 14: Policy-making and planning; 15: Legislation; 16: Economic policies; 17: Coordination of work; 18: Organisations of persons with disabilities; 19: Personal training; 20: National monitoring and evaluation of disability programmes in the implementation of the rules; 21: Technical and economic cooperation; 22: International cooperation.

**World Health Organisation (WHO): Atlas on mental health**

The atlas is a project of the WHO on mental health in the world. The objectives of this project include collection, compilation and dissemination of relevant information on mental health resources in 185 countries. It finds that 40% of countries have no policy, 30% have no programme and 25% have no legislation (WHO: Atlas, 2001).



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The Advisory Committees, whose members are nominated from the Foundation's tripartite Administrative Board and Committee of Experts, provide advice on the design and implementation of the Foundation's programmes and other major activities. The Advisory Committees monitor the development of the Foundation's work, discuss the findings, and advise on the publication and dissemination of the results.

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