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### Definitions of disability in Europe: A comparative analysis: Final report

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**DEFINITIONS OF DISABILITY IN EUROPE:  
A COMPARATIVE ANALYSIS**

**Final Report**

**13 September 2002**

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Directorate-General**

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COMPARATIVE ANALYSIS AND ASSESSMENT OF THE POLICY IMPLICATIONS OF ALTERNATIVE LEGAL  
DEFINITIONS OF DISABILITY ON POLICIES FOR PEOPLE WITH DISABILITIES

CONTRACT REFERENCE VC/2000/O32

BRUNEL UNIVERSITY UK

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## EXECUTIVE SUMMARY

This report provides an overview of the definitions of disability found in the social policies and anti-discrimination laws of member states of the European Union and Norway. The definitions used in anti-discrimination legislation are usually very broad, potentially including people with minor disabilities. These laws focus on the act of discrimination rather than the health status of the person. The definitions used in social policy are more restrictive, as they are used within processes which allocate scarce resources to those whose needs have been recognised. The report discusses in detail the relevance of the definitions of disability used in social policy to the needs that social policies are intended to address.

A wide range of approaches to definition is identified in the study. Impairment-based definitions, often using tables which determine percentages of disability corresponding to specific medical conditions and injuries, define disability for some work incapacity benefits and pensions, and for many employment quota schemes. Analysis of a person's problems in the work environment (which may be the person's previous work environment or may refer to labour market requirements more generally) are also found in work incapacity schemes, while many provisions for care and assistance (e.g. care insurance) focus on a person's capacity to perform activities of daily life. In many states, the approach to work incapacity is not based on a 'snapshot' of impairments or limitations, but instead involves working through processes of investigating rehabilitation options and finding appropriate employment measures. Employment policies for disabled people, with the exception of quota schemes, generally demonstrate a high level of flexibility in the definition of disability, whereby health status is considered alongside other factors influencing employment prospects such as skills and education.

The report shows that different definitions of disability are relevant to different policies, and that attempts to use the same definition across a range of policies can result in the use of definitions of limited relevance, which means that policies may be poorly targeted. The necessity of using a plurality of definitions to ensure relevance raises a problem of coherence in disability policy. People may be designated as disabled for one policy and not for another, and sometimes they encounter gaps in provision as a result. Generally, states address these problems by requiring social policy institutions to coordinate their activities, rather than by trying to establish unified definitions.

In many of the situations which social policy addresses, such as lack of income due to lack of work, there are difficulties in distinguishing between needs arising from disability and needs arising from other disadvantages such as poor local labour market conditions or low education. In some situations, it may not be necessary to distinguish between disabled people and others with similar needs. The report discusses a number of examples from the states studied where non-categorical social policies have been adopted. Most examples are in the areas of social assistance and employment policy. In social insurance, there is often a significant institutional dimension to the use of disability categories, as insurance against work incapacity may be institutionally separated from insurance against other contingencies.

The report presents four models of disability determination derived from two parameters: the degree of medicalisation and the extent of discretion in decision-making. States' locations within the four models can be related to underlying fundamental features of each state's general social policy traditions, notably the pattern of financing for social policy (whether centralised or devolved) and the degree of trust in, and accountability of, doctors and other social policy professionals. Different approaches to disability determination are, therefore, deeply embedded in national institutions.

Despite these differences, there are many common elements in the disability policies of the states studied. States face similar policy problems which may be addressed by supranational coordination within the European Union. Member states have indicated their acceptance of a number of common aims in the area of disability policy, for example concerning the promotion of employment among disabled people and the need to counter discrimination. States will pursue these common aims in different ways which reflect their national social policy traditions, and this report shows that this will entail the maintenance of different approaches to definitions of disability. Nonetheless, there is considerable scope for cross-national exchanges of information and policy learning in this area. This report contributes to this process by providing accounts of the definitions of disability used in states' policies in a standard format, and by providing an analysis of the reasons for adopting different approaches to the definition of disability.

**PART I**  
**INTRODUCTION AND METHODOLOGY**

## INTRODUCTION

### 1.1 Background to the Commission's Tender Document

This report brings together the results of a two-year project financed by the European Commission. The Commission's interests in the definition of disability arise from a number of sources. Disability issues arise in the operation of the principles of free movement and open competition, where EU institutions have competence to develop precise legal and administrative solutions to certain policy problems. Regulations governing the cross-border claiming of social security benefits and access to welfare services have to be administered and, sometimes, reformed. In competition policy, regulations and directives relating to public procurement and state aids address specific issues about subsidies and restrictions on competition relating to the operations of sheltered workshops and other types of disability policy.

In these areas, the general outlines of policy have been agreed by the member states as an integral part of their commitment to the Union. The competence of the Commission to develop regulations and directives in these areas is unquestioned: there is no avoiding the need to find common European solutions to these problems. Important issues arise about, for example, the rights of disabled non-workers to take up residence in another state, or the extent to which barriers to competition may be erected in order to serve social purposes such as providing employment to disabled people. Solutions to these issues require political compromises. This project aims to contribute to the task of finding solutions to these ongoing problems of European integration by enhancing the cross-national understanding of member states' disability policies.

There are also other aspects to the development of EU disability policy, although they are harder to characterise. They involve the creation of a common European space of research, analysis and debate. Components include the development of European statistics and the exchange of information about policy initiatives. In some areas, for example in the field of employment policies, these exchanges have become relatively formalised through the 'open method of coordination', whereby member states submit plans describing their policies and specify the outcomes they are targeting. Different participants no doubt have different views about the uses of this common space. We can note that it is a relatively open space, with non-governmental organisations as well as national governments participating in it. To a large extent, the ideas that circulate in this space have to be mediated through national social policy institutions and processes before they affect the lives of citizens of the Union, and sometimes the relationships between European and national debates can be quite attenuated. Nonetheless, cross-national policy borrowing is important in many areas of social policy.

Some areas of policy raise both specific problems of implementation and issues at the level of policy exchange and debate. The Framework Equal Treatment Directive (FETD), which includes provisions on disability, is one example. The FETD is an instrument of European law and must be transposed into the national legal frameworks of the member states. However, much of its value comes not from the strict requirements of transposition but from its contribution to the framing and visibility of particular issues in social policy.

In the area of disability policy, the common European policy space should also be placed in the context of an international space in which disability policy issues are aired. Most notably, the World Health Organisation (WHO) has endeavoured to promote good practice in the understanding of the concept of disability and the development of methods for gathering information about disability. We discuss the work of the WHO and its relationship to European policy issues in general and this project in particular in chapter 2.

The Commission indicated how it saw this research relating to its social policy work in the tender document. While it noted that differences between member states in definitions of disability have implications for free movement and therefore relate to the issues of legal and administrative competence described above, many of the questions raised in the tender were more concerned with contributing to European-wide research, analysis and debate. The Commission suggested that confusion around the definition of disability was a barrier to the development of comparative analysis and policy evaluation. It highlighted the use of different definitions of disability in different fields of policy, and asked that the study should analyse the tensions between different definitions. (The tender document noted a particular issue of tension between anti-discrimination definitions and employment policy definitions which is explained in more detail in ch 5.) The Commission also gave an indication of how it saw European disability policy developing, noting that there was ‘a move away from a medical model towards a social model of disability’. One of our aims in this study is to identify the different ways in which the member states have interpreted and implemented this move through the development of their definitions of disability.

The Commission asked for ‘an analytical and descriptive account of the main definitions used throughout the 15 member states in respect of anti-discrimination legislation, employment measures and benefit schemes..’. As we explain further below, to provide an analytical account of the definition of disability used in, for example, an income maintenance benefit involves collecting a lot of information. Even if there is a form of words which gives a general definition of the target group for the measure (and such definitions do not always exist), further information is required to discern its meaning in terms of who is included and who is excluded, which is the substantive process of definition in this context. It was therefore necessary to be selective about which laws, measures and benefits would be examined in detail. In this report, we provide three appendices setting out the definitions used in selected employment measures and benefit schemes. The accounts of benefit schemes are divided into income maintenance and support benefits on one hand, and provisions for assistance with activities of daily life on the other. These latter provisions range from small allowances for transport costs to substantial packages of assistance to facilitate independent living for people who might otherwise be institutionalised. The discussion focuses mainly on cash benefits. Issues of defining disability tend to arise more sharply in the allocation of cash than in the provision of services and benefits in kind. Some in-kind provisions are discussed, but we exclude, for example, health service provisions where the assessment focuses on the suitability of particular medical interventions rather than on determining whether the person is disabled or not.

The discussion of anti-discrimination definitions is in the body of the text in chapter 5. Generally, there is much less information about who is included and who is excluded from anti-discrimination laws than for the other types of definitions. The latter are routinely implemented

on a day-by-day basis by administrators, doctors and others, often using written guidance which serves as primary research material. Anti-discrimination laws are implemented with less frequency through tribunal and court cases, and there are few cases which touch on issues of definition except in the United Kingdom.

The selection of measures for detailed analysis raised a number of issues, of which we mention just one at this stage. The tender document refers to ‘definitions of disability’, using a general understanding of the term. To describe the procedure for determining eligibility for an invalidity pension (for example) as a ‘definition of disability’ means using the word ‘disability’ in a wide sense. It could be objected that some of the pensions we discuss are not really ‘disability’ pensions, but are, say, ‘impairment’ pensions, using the term ‘impairment’ in the precise sense defined in the World Health Organisation’s International Classification of Impairment, Disability and Handicap (ICIDH) (see ch 2). Clearly, it would defeat the purpose of the study to leave out provisions which did not meet some *a priori* conception of what disability is about, even if that conception was informed by international standards for defining the terms. The aim of the research is to find out what disability means in the member states, by looking at their policies.

However, this approach presents a converse problem. The member states obviously use different terms for different provisions. If we looked only at the provisions where the state uses the term ‘disability’ we would not obtain comparable data. It was therefore inescapable that we had to define the scope of the study, but without defining disability. We defined the scope of the study by asking national reporters to select provisions in which some aspect of a person’s long-term health status was one of the criteria for allocation. It is very important to note that this means that the provisions discussed in this report facilitate comparison of approaches to definition but do not allow comparison of levels of provision for disabled people (however defined) across states. For example, there are some provisions, particularly those related to social assistance, where benefits depend on health status in one member state while very similar benefits are allocated without reference to health status in another. By using an exogenous definition of disability, such as a survey definition, we would be able to see how disabled people fared in the state which made specific provision compared with the state which made only general provision. This study is not designed for this type of comparison, although it provides the essential background information for such analysis.

Another problem of comparison arises when a state reserves the term ‘disability’ for one subset of its provisions, and focuses its disability policy upon this subset. Other provisions which also depend on health status may be systematically excluded from that state’s own disability policy discourse. For example, in Spain the focus of disability policy is on the target group for the Law on the Social Integration of the Disabled (LISMI), a framework law which is accompanied by specific definitional instruments based on concepts in ICIDH. LISMI is wide-ranging, but it does not encompass the main contributory invalidity pension, for which eligibility is assessed using a different methodology. This exclusion of contributory invalidity or incapacity benefits from the mainstream of disability policy discourse is also found to a greater or lesser extent in other states. Conversely, there are some states where disability policy is very much focused on the recipients of income maintenance benefits, notably the Netherlands and to some extent the UK. One of the aims of this research is to highlight these differences in focus and explain how they affect national disability policies. We see this as being a vital prerequisite to meaningful

cross-national exchanges about disability policy.

The Commission specifically mentioned that its goal in commissioning the research was not to move towards a single standard definition, but rather to develop a framework in which different definitions could be located and compared. In developing this framework for comparison, we had two main sets of concerns in mind. First, any framework had to be relevant and meaningful in describing the disability policies of the member states. As we explain further in chapter 2, we were very aware of the difficulties encountered in implementing questionnaires in disability policy, where the framing of the questions can result in high levels of non-response or tentative responses revealing uncertainty about the meaning of the question. We addressed the problem of country-specific relevance by creating a fairly open format for the national reports, relying on the expertise of the reporters to obtain meaningful accounts of national disability policies. Having got the reports, it was then up to the project team to create a framework for comparison which would retain at least some of their richness of insight and detail.

The second set of concerns was that the framework had to be relevant to European-level policy debates which relate to the definition of disability. As noted above, these debates cover a wide range of issues, from social security coordination to the implications of the social model of disability. While these issues seem very different, they do highlight some similar things. Accounts of how decisions are made about eligibility and entitlement were needed for all the different purposes, but in making these accounts comparable, it was also necessary to make them interpretative. Contextual information about the national system for benefits and employment provisions was needed, but clearly the contextual account is selective. Finding what to select for the discussion of coordination was relatively straightforward, as the relevant regulations and ECJ decisions set out the factors which are considered relevant to coordination. Giving an account of the policy context which would be relevant to analysing the application of the social model was a much greater challenge. In the next section, we present an account of the social model of disability and explain how it influenced the research design.

## **1.2 The Social Model**

The social model is usually explained by reference to its opposite, the medical model. The medical model views disability as a personal problem, directly caused by disease, accident or some other health condition, and capable of amelioration by medical interventions such as rehabilitation. The social model, by contrast, sees disability not as an inherent attribute of a person but as a product of the person's social context and environment, including its physical structure (the design of buildings, transport systems etc) and its social constructions and beliefs, which lead to discrimination against disabled people.

A close relative of the medical model is the 'social welfare model' (Waddington and Diller, 2000) which sees medical impairments as automatically resulting in disadvantage and exclusion, which can be ameliorated by cash benefits and other social welfare policies. It is often assumed that traditional social policies incorporate the social welfare model and are, therefore, based on a medically oriented interpretation of the nature of disability. In this research we have not made this assumption. Instead, we have treated the question of how social policies define disability as being susceptible to empirical enquiry.

It is often said that the social model has implications for the definition of disability. To 'define' in this context is to explain the nature of disability. For example, trainee social workers may be guided through the application of the social model by being given case histories of people with disabilities and asked to interpret and describe the nature of their limitations and disadvantages. The trainee is taken through an exercise in social analysis and understanding.

When social policy agencies develop definitions in the course of implementing targeted policies, they engage in a different process of definition. They 'define' in the sense of indicating boundaries and delineating who should be seen as being in the designated category. The social model does not give straightforward insights into how the boundaries between disabled and non-disabled people should be drawn in social policy. Indeed, many advocates of the model see the process of drawing boundaries as pernicious in itself.

The social model does not give straightforward insights into how definitions in social policy should be formulated and operationalised, but it does raise a number of important issues for social policy. First and foremost, the social model implies that policies should be directed at the removal of barriers to full participation for disabled people, rather than 'problematise' the disabled person. This suggests that policy should be concerned with identifying disabling situations, rather than disabled people. We can see this approach in action in the development of regulations on building design and transport infrastructure which are intended to prevent the construction of new disabling situations and to reduce existing physical barriers.

This implication of the social model draws policy-makers' attention to the potential for enhancing society's stock of enabling (as opposed to disabling) assets. The paradigmatic example of an enabling asset is a wheelchair ramp. Once the ramp is installed, it is non-rival in consumption: one person's use of the ramp does not reduce the access available for another. The marginal cost of using the ramp is zero (an additional user does not cost anything, beyond trivial wear and tear). Because of this feature, it is not necessary to differentiate between disabled people and others in order to allocate access to the ramp.

While wheelchair ramps and curb cuts are often given as examples of these types of policies, their scope is somewhat wider. Design is non-rival in consumption (the marginal cost of re-using a design comprises only the cost of transmitting the design data, e.g. photocopying the plans), so 'enabling' design innovations also come into this category of good. Measures to ensure health and safety in the workplace environment are also potentially enabling and non-rival. Note that non-rivalry does not mean that these goods are free: on the contrary, these measures may be expensive to introduce. However, once introduced, they do not have to be allocated selectively.

Symbolic policies which seek to influence attitudes and change general patterns of behaviour are non-rival goods - indeed, they rely for their effectiveness on a wide social uptake. Symbolic disability policies do not require precise delineation of what is meant by disability, although there may be issues about what the general public understands by disability which favour or disadvantage particular groups (for example, people with mental illness are not always understood to be disabled), so a symbolic policy may have to address issues about definition in order to be effective. As described above, the social model is very influential in defining

disability in this sense.

This study looks at the definitions used in social policies which allocate resources which are rival in consumption. The competition may be for budgetary (financial) resources, or it may be for ‘advantages’ such as special consideration (e.g. extra points) in the allocation of jobs, training places or other scarce social provisions. It is possible to formulate extensions to the social model which indicate how its general principles might operate in the conduct of these types of policy.

One possible extension is to explore the scope for administering social policy without using definitions of disability. Policies could establish general rights, potentially exercisable by any citizen, but likely to be of greatest value to those with a disability. Examples of such policies are most often found in employment, so their value is limited to those disabled people who are workers. Examples include the right to time off for medical treatment and the right to flexibility in working hours. Work environment measures which require the employer to ensure that each worker is appropriately provided for may also be of particular value to some workers with disabilities. General non-discrimination protections (the right not to be arbitrarily and unfairly treated) may also be of particular value to people with disabilities, but if a right is provided specifically for disabled people to the exclusion of others, a definition will be required. We discuss this important case further in chapter 5.

The structure of many benefits and measures operated by European welfare states can be examined critically from a social model perspective. The social model challenges some of the basic values and assumptions underpinning the European welfare states. In particular, it questions the way categories are developed in order to allocate resources. The welfare state, as a non-market system of allocation, relies heavily on welfare professionals to discern needs and make appropriate allocations. The social model challenges the use of medical norms to determine who belongs to the category ‘disabled’ for the purposes of social provisions.

However, the social model is silent on aspects of categorisation other than the use of medical norms. There clearly are other aspects to social policy categorisation, most obviously in delineating other social policy categories, such as unemployment. One approach to interrogating the construction of disability categories is to ask whether disability categories could be subsumed into other categories, and how the boundaries between disability and other categories are delineated. Asking this question opens up issues about what is distinctive about disability as a source of disadvantage. We explore these ‘boundary’ issues further in chapter 4.

The social model is also silent on the impact of other allocative principles used in social policy, such as contribution requirements and means tests. It could be argued that, if the disability categories used in social policy are invalid and discriminatory, a policy such as a basic citizen’s income would be more in accordance with the underlying principles of the social model. The social model might also be taken to imply that it would be desirable to ‘mainstream’ disability provision, for example by incorporating employment provisions for the disabled within the policies managed by the main employment service. Some member states have moved in this direction, as is discussed in chapter 4.

It must be noted that, while the social model has been endorsed by the EU institutions, the

possible implications being noted here have not been endorsed. There are problems with mainstreaming and relying on general rights to provide for disabled people. Often, superior provisions are made for the special category of disabled people. General rights may not be defined in a way which recognises the particular needs of disabled people, and the resources allocated to disabled people under general provisions may be reduced by competition from other needy groups, such as the elderly. In this research we have endeavoured to contribute to the policy debate on these difficult questions by identifying relevant policy initiatives undertaken in the member states and discussing their implications.

### **1.3 A Social Policy Perspective on Definitions of Disability**

As the previous section indicated, it is possible to take different approaches to the definition of disability which operate at different levels. A definition may be an explanation of a concept: it is in this sense that the social model (re)defines disability. A definition may also be a form of words which provides a precise statement of the nature or essential qualities of a thing. We can find forms of words defining who is and is not disabled in this sense in legal acts and regulations in the fields of anti-discrimination, employment and social security. Where possible, we have assembled information on the forms of words used in social policy legislation and regulations and we reproduce these in the appendices under the heading 'general definition'. However, not all disability policy measures provide a general definition of disability in this sense. Sometimes, the purpose of the measure is stated rather than the definition of disability, e.g. '[name of pension] is payable to insured persons who are unable to work due to incapacity' or '[name of benefit] is a means-tested allowance for persons with a specified disability'. Clearly in these examples we need to find out what is meant by 'unable to work due to incapacity' or 'a specified disability' before we can say anything about how disability is defined. Another approach found in law is to specify the procedure for defining disability rather than the definition itself, e.g.: 'a person is disabled if determined to be so by a Commission established for the purpose'. Here we need to know what information and rules the Commission uses to make its decisions before we can see how disability is defined.

Whereas laws governing provisions which are implemented through administrative processes often do not contain a detailed definition of disability, the opposite is true in the field of anti-discrimination legislation. A great deal of effort has been invested in finding appropriate forms of words for anti-discrimination legislation. The definition contained in the Americans with Disabilities Act has become the focus for a large academic and policy literature. This reflects the mode of implementation of this area of law. The form of words has a central place in the process whereby judges and other adjudicators determine how the facts of a particular case relate to the law. Through cases, a body of interpretative data is gradually accumulated which gives meaning to the words.

In this study, we were faced with the task of researching definitions which are mainly implemented through administrative rather than judicial processes. There is case law in some areas arising from appeals against administrative decisions, and we could have tried to study definitions of disability by analysing the case law. This would have given us an insight into the problematic and disputed aspects of disability definition in those areas of social policy where appeals to judicial-type institutions are available and are utilised, and where reasoned decisions are published. Another method would be to select particular medical conditions which are

known to present issues about the certainty of the diagnosis (such as chronic fatigue syndrome) or the impact of the condition on functioning (e.g. diabetes) and to compare how these conditions are handled in the administrative processes of the states covered in the study. These research methods might produce interesting results, but we felt that the logical first step in researching this subject was to identify the everyday processes of definition which are involved in the routine conduct of social policy. To do this, we obtained information about administrative processes, along with commentaries on how definitional issues were perceived and addressed by actors involved in social policy formulation and implementation. Our findings about administrative processes are reported in the appendices and summarised in chapters 3 and 4. We describe the different types of instruments used in assessment (impairment tables, lists of capacities, descriptions of work requirements, etc), the personnel who make the decisions and the institutional contexts in which they work. Chapter 4 presents four models of disability assessment in which the key parameters are the extent of reliance on medical evidence and the degree of discretion vested in the decision-maker.

This approach to framing issues around the definition of disability clearly covers quite different ground to the debate over the definition of disability in anti-discrimination legislation. The constraints and imperatives of administrative decision-making are different to those of the judicial process. Control of administrative costs and timeliness are key issues in administrative processes, creating pressure for parsimony in informational demands. Consistency between decision-makers is an important aim in the design and management of administrative processes, although our analysis suggests that different institutions have different ideas about what consistency entails and how it might be maintained. But perhaps the most important difference between administrative and judicial processes stems from the management of budgets. The maintenance of financial control and the targeting of financial resources to the highest-priority recipients are central concerns in the administrative conduct of social policy, whereas budget management is not generally a concern of the judiciary.

The explicit consideration of resource allocation in the administrative processes of social policy raises a further set of issues which are discussed in chapter 3. In that chapter we examine the definition of disability from the perspective of the problem of establishing the boundaries of categories in social policy. Categorisation is one of the basic techniques used to determine the allocation of resources in social policy. In previous work (Bolderson and Mabbett, 2001), we noted that the use of disability categories in social policy is under challenge from several directions. Not only are advocates of the social model critical of the social welfare approach to disability (as discussed in s.1.2); policy-makers are concerned about rising numbers on disability benefit rolls. Disability categories present particular problems in identifying who belongs to the category and who does not, and the boundaries between disability, unemployment and early retirement have proved to be permeable and subject to manipulation for financial and political reasons.

In chapter 3 we draw out from the national reports a number of examples of how these boundary issues present themselves in European states. In some states, an increased emphasis on activation and participation in policy towards the unemployed has also influenced approaches to disability policy. Re-conceptualisation and re-diagnosis of the problems of unemployed people, some of whom may have limited employability due to low education and skills or social problems, has been accompanied by the development of unified employment

policies towards different groups of people who are 'hard to place', including those with disabilities.

The aim of promoting employment among disabled people has also influenced income maintenance policies. The OECD has advocated a re-definition of disability in cash benefit provision which does not equate disability with inability to work (OECD, 2002). Instead, a disability benefit could be paid to those in work as well as out. Several states have policies in which benefits are payable to disabled people in or out of employment to help meet extra costs associated with their disability. The counterpart of the OECD's proposal would be that 'ordinary' income maintenance for non-working disabled people would be aligned with unemployment benefit, or, more generally, that income maintenance policy for the working age population would be non-categorical. Some states already do not differentiate between unemployment and disability in their general social assistance scheme, and others are making policy changes which reduce the significance of the categorical boundary (for example, by aligning benefit rates). However, many states would face significant institutional obstacles to adopting a non-categorical approach. This is particularly the case for insurance benefits, where the institutions delivering unemployment and disability insurance are often separate, and categorisation is therefore critical in assigning institutional responsibilities.

While unemployment and disability insurance are often institutionally separate, there are institutional linkages between disability and retirement insurance in some states. In these states in particular, disability benefit receipt is strongly age-related (OECD, 2002, Table 4.8). A number of states blur the boundary between disability and old age by operating early retirement provisions which require some indication of a health-related limitation. Policies to raise the effective retirement age, which a number of states are introducing in response to population aging, have implications for the use of disability benefits as a route to early exit from the labour force.

In the field of assistance with activities of daily life, there is a boundary issue between 'normal' aging and disability. Some states have provisions for the disabled which are considerably more advantageous than those available for the frail elderly, raising issues of equity and leading to pressure on category definitions, as the incentives to obtain a disability classification are strong. Other states have merged some provisions for the frail elderly and the disabled, but then face the converse problem that the resources available for younger disabled people are crowded out by the claims of the elderly.

In summary, this report provides information and analysis relevant to a number of current issues about the use of disability categories in social policy. It shows how European states construct such categories and for what purposes, and also gives some insight into the circumstances under which disability categories might be avoided in favour of non-categorical approaches. It shows how well-known general features of states' social policy structures, such as the extent of fragmentation or integration of providers, the use of means tests and the role of the contributory principle, exert indirect influences on disability categorisation. It indicates how an important new form of regulatory social policy, anti-discrimination legislation, might be thought to relate to more 'traditional' social policies, while also showing that long-established budgetary social policies are themselves subject to reforms and developments which reflect new thinking about disability.

## THE RESEARCH CONTEXT AND RESEARCH DESIGN

A number of studies have been undertaken which are relevant to this research project and cover some of the same ground. Problems of comparing data on disability across countries have been addressed in studies of the EU states (Rasmussen et al, 1999) and the OECD (Gudex and Lafortune, 2000). There is a particularly rich body of research on the employment of people with disabilities which often touches on issues of definition (e.g. Prins et al, 1992; Thornton, Sainsbury and Barnes, 1997). A European Group of Experts on Employment for Disabled People was created under the auspices of the European Commission in 2000 (van Elk et al, 2000); one of its first tasks was to identify and develop comparable statistics on the employment status of persons with disabilities.

In this chapter we review in detail three projects of direct relevance to this research (s.2.1). In s.2.2 we explain how the research design for this project differs from related studies and discuss some of the consequences for interpreting the findings.

### 2.1 Related Research

#### *ICIDH and ICF*

In the last 30 years, the World Health Organisation (WHO) has taken a leading role in promoting the collection of comparable cross-national data through the development of conceptual frameworks relating to disability. The International Classification of Impairment, Disability and Handicap (ICIDH) was developed in the 1970s and published by WHO in 1980. The classification defined three terms: impairment (functional/structural abnormality of the body), disability (activity or behavioural problems at the level of the person as a result of impairment) and handicap (social disadvantages arising from disability). ICIDH was a framework which encouraged doctors and other users to think about health in a wider context than pathology and treatment. It can be seen as part of a research programme which also produced important findings about the connections between socio-economic position and health, and raised issues about health inequality, access to health care and structures of health system financing.

ICIDH was very influential and has left its mark on the assessment systems described in this research. Two systems which make explicit reference to ICIDH are the French 'Guide Barème' and the Spanish 'Valoración de las situaciones de minusvalía' (VM). These two schemes develop the ideas in ICIDH in rather different ways. In the French scheme, the severity of an impairment is measured by looking at its disabling effects; in other words, disability provides a unified concept or numeraire for scaling and combining diverse impairments. The approach in the Spanish VM is somewhat different: impairment, disability and handicap are all seen as elements in the total 'score' given to a person for the purpose of entitlement to benefits and access to services. The very fact that ICIDH could be implemented in these different ways signals that it was an open framework rather than a definitive schema for working out who is and is not disabled. Despite this openness, the framework met with criticism, especially about

the implicit linear connections it made between impairment, disability and handicap.

The WHO's revision of ICIDH, now called the International Classification of Functioning, Disability and Health (ICF), was finalised in 2001. It retains and even increases the openness of the original framework. In particular, the term 'disability' is no longer defined within the scheme; instead, the whole picture relating to the wide concept of disability is captured by looking at three dimensions: impairments of body structures and body functions, activities and participation.

An important feature of the approach which has been adopted in the ICF is the 'universalisation' of the understanding of disability (Bickenbach et al, 1999). This approach 'recognizes that the entire population is "at risk" for the concomitants of chronic illness and disability' (Zola, 1989, p.401). The ICF scheme does not provide thresholds for defining who is disabled and who is not; instead, it recognises aspects and degrees of disability across the whole population. Many statistical uses of disability data do not require the establishment of thresholds. For example, statistics summarising the health of the population may incorporate elements related to disability in a continuum of health status. There is no need, in this approach, for a definition of who counts as disabled and who does not. It follows that the international comparison of disability statistics does not necessarily require threshold issues to be resolved.

The universal approach allows thresholds to be set by the researcher for particular purposes. Schneider (2001) highlights the distinction between *a priori* and *a posteriori* approaches to definition. The *a priori* approach is to ask a question like: 'Are you deaf or blind or do you have a physical disability?' The answer to this question classifies a person as disabled or not disabled. *A posteriori* approaches are found in censuses and surveys which are designed in ways which allow for multiple thresholds dividing the disabled and the not-disabled, or subgroups of the disabled. These sources collect information which enables users to develop the thresholds appropriate to their enquiry by selecting the most relevant questions and responses and determining the critical codings. Different enquiries can draw different demarcation lines.

The international comparison of social policies is fundamentally concerned with how thresholds are set by administering institutions. The objective of the research is to understand the political and administrative decisions involved in determining thresholds. This is a different research problem to the problem of constructing a dataset which can provide the basis for research into aspects of disability. We can expect that social administrators will acquire information selectively, investing in data which will be relevant to their decision-making.

#### *The Council of Europe: Assessing Disability*

In 1997-2000 the Council of Europe (CE) conducted a study on 'Assessing Disability in Europe' (Council of Europe, 2002). Like the current study, the CE study was concerned with situations where benefits or services were allocated or given on the basis of some test of disability. The study divided the conditions for the award of benefits into two groups:

- i. personal and demographic factors such as age, income, contribution record etc
- ii. the requirement to be disabled.

The CE's enquiry focused on methods of assessing this latter requirement. The study found that there were four general methods of assessing disability in use: the barema method, care needs assessment, the measurement of functional capacity and the calculation of economic loss. Very

detailed information is provided on different national baremas (tables showing a certain percentage of disability corresponding to specified impairments) and we have refrained from replicating this information in our findings. However chapter 3 below provides more detailed information about the other methods of assessment than can be found in the CE report.

The questionnaire developed by the CE partly reflected official CE positions, concerning (a) the use of multi-disciplinary teams, (b) the application of the principle of ‘rehabilitation before allowance’ and (c) the use of WHO standards and concepts (reference is made to the old ICIDH, still current at the time the study was undertaken). Questions on these issues relate to CE Recommendation No. R (92) 6 on a coherent policy for people with disabilities. The Recommendation also states that people with disabilities should have access to a minimum livelihood, specific allowances and a system of social protection, and the questionnaire asked respondents to list their provisions under the headings of long-term incapacity benefits, short-term incapacity benefits, benefits for children, care allowances and personal assistance in education, vocational training, technical aids and work reintegration. The coverage of the study was therefore wider than the present one in including education provisions and benefits for children. The study did not cover anti-discrimination legislation, which was the subject of a separate study two years ago (Council of Europe, 2000).

The interpretation of the questionnaire responses presented several problems which are acknowledged in the commentary in the CE report. In particular, ‘legal definitions like invalidity or incapacity do not necessarily refer to the same concepts... [T]erms like impairment or disability are often used alternatively and not always with reference to the ICIDH definitions’ (Council of Europe, 2002, pp.44-45). Despite the considerable efforts made to ensure that respondents understood the questionnaire, different respondents interpreted the questions in different ways (p.12).

The draft reports from the CE study were helpfully provided to us at the beginning of this project, in October 2000, and contributed to several of our decisions about the research design for this project. In particular:

i. In this study we have not made an *a priori* separation between the ‘disability test’ and other conditions for the award of benefits. We have looked more widely at policies for people with disabilities to see how the design of those policies - specifically, the way in which recipients are selected and others are excluded - can illuminate our understanding of what is meant by the term ‘disability’ in social policy.

ii. The difficulties with the questionnaire contributed to our decision to ask National Reporters to provide narrative accounts of disability determination for this project, using a checklist to ensure that relevant points were covered.

One of the Council of Europe’s main aims was to improve cross-national understanding of different disability assessments and to see whether common approaches could be developed which would facilitate the cross-border administration of disability-related conditions for benefit entitlement. Some participants in the study seem to have hoped that the barema method could provide a common platform for cross-national coordination, through the development of a European Barema, but the study concluded that baremas are becoming less widely used and, in any case, have certain fundamental flaws. In chapter 6, we have taken a different approach to the issues arising from the cross-border movement of people in Europe. The CE study takes the

current pattern of exportability in disability provisions as given, and looks at how better understanding at an administrative level could improve the handling of cross-border cases. The present study looks at the principles governing exportability and considers whether particular benefits should be exportable or not in the light of the criteria established by the European Court of Justice and the wider aims of free movement as set out in the Treaty.

#### *The OECD: Transforming Disability into Ability*

Shortly before our study got underway, the OECD launched a project 'to find out which combinations of [disability] policy are promising and to demonstrate how inconsistencies in some combinations can counteract the intentions of disability policy' (OECD, 2000, p.5). The OECD study was, therefore, addressed to a particular policy problem: the conflict between income maintenance programmes for disabled people and the promotion of 'participative' policies - meaning, in this context, the promotion of employment. The following discussion is based on the draft final report (OECD, 2002).

The design of the study postulated that disability policies could be grouped according to two orientations: integration/activation and compensation/income replacement. Disability policies were classified according to their orientation, and information about the policies was summarised and scored in order to develop a disability policy typology. The typology was designed to explain (a) disability benefit reciprocity rates and (b) employment rates of disabled people. Both survey and administrative data are used, and a number of important issues are raised by comparing these two sources of data.

The main aim of the OECD study - to investigate the impact of different policy orientations on cross-national differences in benefit reciprocity and employment rates - is quite different to the aim of this research project. However, there is a considerable amount of information in the OECD study which is illuminating about differences in definitions of disability and their impact on administrative data such as benefit reciprocity rates. The OECD study explores a number of ideas about how disability decision-making affects benefit reciprocity, including for example the effect of assessment by treating doctors (general practitioners etc) compared with doctors employed by social insurance institutions, and the effect of assessing work ability by reference to past occupation compared to assessment based on opportunities in the general labour market. Furthermore, as is discussed in chapter 7, the definitions of disability used in income replacement policies were identified as a problem for the development of a coherent disability policy.

The study looked at the extent to which patterns in benefit reciprocity and employment rates could be explained by different policy parameters and policy orientations. Generally, the results are ambiguous. For example, the cross-national relationship between the strength of integration-oriented policies and the employment rates of disabled people is quite weak. These results are relevant to the present study, as they suggest that there are no simple relationships between policies, including definitions of disability, and outcomes, whether these are measured using administrative or survey data.

## 2.2 The Research Design

A central feature of the design of the project was that it was intended as a collaborative effort between the 15 member states (and Norway, which has been included). We held workshops in Brussels early in 2001 and again in 2002 with the national reporters whom we appointed at the outset. The reporter for Luxembourg was not able to continue to participate in the research after the initial meeting, so Luxembourg is not included in this study.

The national reporters were experts in the field of disability policy research and did not act as national representatives. Many researchers and activists have argued that it is those with experience of disability who can give the most valuable insights into its meaning. Conflicts between the rules and practices of institutions and the experiences and understandings of the people they affect are apparent in many studies (e.g. Blaxter, 1976). This project is oriented towards the rules and practices of institutions rather than the experience of individuals. The project did not set out to research disabled individuals' own experience of the process (how they feel about it, or fared by it). Instead, the research sought to capture the nature of member states' policy objectives and policy concerns regarding the definition of disability.

Three background papers were written for the first workshop. One reviewed the conceptual literature and its relevance to the project, one summarised recent applied cross-national research relating to disability, and one reviewed the current development of EU disability policies. The empirical work to be undertaken by the national reporters was developed jointly with them during the two days of the workshop and a 'check list' (later referred to as an 'alert list') of questions to be addressed was constructed. The list, the agreed format of the proposed national reports, and the background papers are on the project website:  
<http://www.brunel.ac.uk/depts/govrn/research/disability.htm>.

### *Selection and Description of Provisions*

A key decision taken at the workshop was that national reporters could choose the benefits and services to be discussed, provided that they included, at a minimum, one from each of the areas required by the Commission (social security, employment, and anti-discrimination measures) plus any others which took distinctive or innovative approaches to the definition of disability. Given the time available to the reporters, it was important that they should not feel that they had to give a comprehensive overview of each state's current provisions in the field of disability. Nor were they asked to report on the details of contribution requirements, means tests and other criteria (much of this information is regularly collected by MISSOC in any case).

However, national reporters found that it was necessary to provide quite a lot of contextual information about the provisions being discussed. Fundamental to our whole approach is our endeavour to put the determination of disability into the context of specific provisions. It is necessary to have at least a sketchy understanding of the provisions before one can understand the definitions, and the process of definition may be difficult to disentangle from other criteria governing access to provisions. In the Appendices, the first part of each country summary describes the social policy context, setting out how provisions for disabled people relate to provisions for others with similar needs but no significant health indications. Important variables include non-disability criteria such as means tests, contribution requirements and age limits. Potentially, the contextual information could be very extensive, and we would not claim

to have identified all the relevant features of the social policy context for all the member states, but a number of important insights emerge from the data we do have.

Having outlined the social policy context of the provisions chosen for study, the national reporters described assessment processes with reference to the alert list. This had three main parts:

- i. Descriptions of disability. This part comprised a list of statements which national reporters could use or ignore, for example: ‘there has to be a medical diagnosis of a condition’ or ‘there are restrictions in ADLs (e.g. washing, dressing, eating, mobility)’.
- ii. Methods of assessment. Again a list of possibilities was given, e.g. medical examination, self-assessment, observation in performing specified tasks. This section also alerted the national reporters to specify the personnel involved, e.g. doctors, labour market specialists etc.
- iii. Instruments used in measuring disability. Possibilities ranged from statutory listings of impairments (baremas) to information about the person’s characteristics and background (age, education, availability of transport etc).

### *Access to Information*

The reporters encountered some problems of access when they set about finding out in detail how disability was determined. There are pronounced differences among the member states in the level at which the main components of the definition of disability are established. In some states, there are formal instruments which have national legal standing. In others, the agencies undertaking the determinations have established guides and rubrics. In yet another group of states, formal instruments are avoided and the professional skills of those undertaking the assessment are relied upon.

Administering institutions were prepared to provide copies of forms, rubrics and other instruments of assessment, although sometimes approval from head office or senior officials was required. Some institutions are very open and have placed a lot of relevant material on the Internet. Difficulties of access can arise when lower-level officials are aware that their daily practices are not completely in conformity with written rules and guidance. In some circumstances, officials speak freely about the difficulties of implementation but sometimes they fall back on ‘standard answers’. In the states where audit institutions investigate and publish reports on administrative practices (notably Sweden and the Netherlands in the area of disability), there appears to be more willingness to discuss implementation problems than in situations where these problems are normally hidden from public view. Some states are considerably more open than others about the resource constraints facing the administration: for example, both the Swedish and Dutch reporters drew attention to the likelihood that some procedures were not followed and certain ‘shortcuts’ preferred because of the limited time administrative staff have to make their decisions. It may be the case that some other systems are better resourced: for example, the administration of EMR in Germany involves the collection of a great deal of information over a much longer time scale than is allowed in some other states. In the discussion of different decision-making models in chapter 4, we suggest some reasons for this, notably the integration of health service provision with disability decision-making.

### *The Appendices*

When we came to develop the appendices we found that describing assessment processes in a parsimonious way to highlight issues for comparison was quite difficult. It might seem

straightforward to construct a framework for interrogating definitions which indicates whether the medical model or the social model is being applied. Definitions which refer to a person's medical condition and which are implemented by doctors might be taken as applying the medical model, while definitions which refer to a person's social context could be said to apply the social model. In practice, few assessments can be classified readily in these terms. The data collected in this study show that disability assessment very often involves complex combinations of medical and social information.

The data in the appendices are divided into two parts. The first part gives information about the policy context while the second focuses on the assessment process. The headings in the appendices differ slightly between the three main areas of provision covered: income support and maintenance, employment provisions, and assistance with activities of daily life and provisions for independent living. However, the main elements are common across these areas and can be summarised as follows.

1. The general definition used or decision to be made. In a number of cases there is no overarching definition or the general statement leaves key terms such as 'incapacity' undefined. However, there are some examples where the general definition gives an interesting insight into the policy approach.
2. Rules and instruments. In the summary of income support and maintenance benefits, the information on rules and instruments is broken down into components: diagnosis, impairment, and standardised descriptions of physical and mental capacity, working life and daily life. In the summaries for other provisions (where assessment processes are generally much less elaborate), the nature of any instruments used is described under a single heading.
3. Personnel. The personnel involved may be doctors, nurses, employment experts, rehabilitation therapists, social workers, multidisciplinary teams, and/or clerical and administrative staff. As explained in s.3.2, it is important to have information on the institutional affiliations of the personnel, as well as their skills and expertise.
4. Observation in context/ circumstances specific to the person. In both employment and ADL assistance provisions, it is possible for the assessor to observe the person doing relevant activities in the workplace or in the home. In the income maintenance area, there is no obvious domain for observation in context, but the assessor may take into account specific factors such as the person's work history, education and skills, and other personal and social circumstances.
5. Role of the disabled person. In the income maintenance area, the disabled person generally has no role in the process by which he or she is designated as disabled beyond making an application and cooperating as the subject of the assessment. In the employment area, the disabled person may have a larger role in coming forward for measures and indicating preferences about the type of placement sought. In the area of assistance with ADLs and independent living provisions, the role of the disabled person in defining his or her needs is potentially significant.
6. Role of employers. This is potentially relevant to both employment and income maintenance measures. Employers may have a role in initiating or supporting applications for a person in

employment to be designated as disabled. Employers may also have specific responsibilities towards employees who become disabled which arise on the path towards income maintenance benefits.

The analyses in the appendices are organised not only country-by-country but also provision-by-provision. It must be noted that the appendices only include provisions discussed in the national reports, which, as explained above, were selected by reporters to illustrate different approaches to definition. The coverage of provisions is therefore incomplete, although the coverage of definitions is intended to be indicative of the range of relevant approaches.

The first workshop for the national reporters and the project team took place in February 2001, and the national reports were written in March-June 2001. Subsequently, there were ongoing exchanges between the project manager and national reporters as the Appendices were prepared and checked. This process was largely completed by the time of the second workshop, in March 2002. The information in the Appendices is, therefore, current as at 2001. Where appropriate it has been updated to 1 January 2002.

**PART II**  
**RESEARCH FINDINGS**

### DEFINITIONS OF DISABILITY IN SOCIAL POLICY

As explained in chapter 1, our research looked at definitions of disability in the context of social policy provisions. The provisions discussed use allocation rules which include criteria relating to health status. This chapter examines the allocation rules used in the areas of assistance with activities of daily life, income maintenance and employment measures. Our aim is to describe and explain the definitions used by setting the social policy context of the provisions, and to raise issues about whether the definitions used are relevant and appropriate.

In their review of disability income policy in the USA, Mashaw and Reno (1996) argue for straightforward linkages between disability definitions and social policy purposes:

‘A definition of disability based on need for assistance with activities of daily living (ADLs) is appropriate for determining eligibility for publicly-financed services that assist with ADLs.

‘A definition of disability based on need for and likely benefit from vocational services is appropriate for determining eligibility for publicly-financed vocational rehabilitation (VR) services.

‘A definition of disability that encompasses all who are at risk of discrimination in employment or public access is appropriate for determining who is covered by civil rights protection.

‘A definition based on loss of earning capacity is appropriate for determining who is eligible for public or private cash benefits to replace part of lost earnings.’ (Mashaw and Reno, 1996, p.24)

Mashaw and Reno draw attention to some situations where definitions and purposes appear not to be aligned, and we give some similar examples below. We also address a further set of questions which emerge from the comparative nature of this study. We examine whether a definition of disability is always needed to allocate access to social services (including assistance with ADLs), employment services (including vocational rehabilitation), and income maintenance benefits (including compensation for lost earnings). What is the rationale, in the context of each provision, for including disability among the allocation rules? What is the relationship between disability provisions and other social provisions which respond to similar needs or situations?

Alongside the allocation rules which relate to health status, each disability provision has other rules which are also applied to other categories created for the administration of social policies, such as the unemployed, families with children, the elderly etc. Examples of these other rules are means and affluence tests and contribution requirements. For the purposes of this discussion, we call these rules ‘non-categorical’. In this chapter, we consider the issues involved in drawing categorical distinctions between one needy group and another in social policy, and also discuss how the non-categorical rules interact with the categorical rules which define disability. In the following discussion, we consider the connections between health status and needs in the areas of assistance with ADLs and promotion of independent living

(s.3.1), income maintenance and support (s.3.2) and employment provisions (s.3.3). In section 3.1 we first examine the relationship between diagnostic and other health status information and needs assessments, and then turn to examine the role of non-disability criteria such as means tests in allocating assistance with ADLs. In section 3.2 we identify three different ways in which the states studied determine work incapacity, and then examine the interaction between disability and non-disability criteria in determining eligibility for benefits. Section 3.3 on employment provisions is structured differently. Different approaches to definition are taken in the administration of different types of employment provision, and these are divided into three groups for the purposes of the discussion: specific disability-related interventions, general employment services, and quota schemes.

### **3.1 Assistance with ADLs and Promotion of Independent Living**

#### *Definitions of Disability*

An appropriate definition of disability for the allocation of assistance with ADLs rests on drawing connections between health status and the ability to perform essential tasks. In the area of assistance with ADLs, the connections between health status and needs seem to be quite natural. The need for help with basic elements of self-care, such as eating, moving and personal hygiene, can generally be taken to stem directly from health problems. Unless the environment is very adverse (e.g. the person is homeless), these are things people, other than young children, usually do for themselves. The assessment of the need for help in performing this narrow range of activities can therefore be understood as an assessment of disability.

However, the structure of entitlement to assistance with ADLs in the European states deviates from this natural pattern in several respects. The first point to note is one highlighted by Mashaw and Reno: that definitions and purposes are not always aligned. In a number of states, assistance with ADLs is only available to recipients of disability income maintenance benefits (in several states, the most extensive ADL assistance is confined to recipients of industrial injury and occupational disease benefits). To qualify for ADL assistance, recipients have to pass two types of test in sequence: first a test of inability to work and then a test of limitations in performing ADLs. This structure might reflect an implicit assumption that work always involves more complex, difficult and demanding activities than the basic activities of daily life, so a person who cannot perform (some of) the latter is necessarily too disabled to work. That this assumption is not valid is fairly evident on reflection. Work may involve abilities to perform highly specific activities which are compatible with disabilities in some basic ADLs.

This point is widely understood in the European states, but this does not mean that states can readily introduce reforms which detach ADL assistance from work incapacity. There are important institutional aspects to the ways in which definitions of disability are used to allocate resources in social policy. In many states, assistance with ADLs for the work-incapacitated is financed by the bodies providing insurance against work disability. A new source of finance would have to be found, and a new allocation of institutional responsibilities undertaken, in order to introduce an 'independent' ADL assistance scheme. For example, Portugal used to have a structure where only the most severely work-incapacitated could be assessed for assistance with ADLs (giving the status called 'grande invalidez'). Recently, it has introduced a separate assessment for assistance with ADLs. The scheme now covers a much wider range

of potential recipients than previously, including old age as well as disability pensioners, and those in non-contributory as well as contributory schemes. However, it still only covers pensioners; it does not provide benefits to people in work.

Turning to states which provide assistance with ADLs independent of work incapacity, we find some hidden complexities in the proposition that ‘a definition of disability based on need for assistance with ADLs is appropriate for determining eligibility for services that assist with ADLs.’ Member states do not all use exactly the same ADLs in their assessments and, furthermore, the assistance they provide does not necessarily ‘match’ the limitations they assess.

Certain core ADLs have a long history of use and are commonly referred to across the member states: these include abilities to sit, lie down and get up from chairs or out of bed (‘transfers’), to maintain personal hygiene and to dress and eat. Others which are found less consistently include mobility and transportation-related activities and ‘social’ activities broadly defined, such as housework and household management, communication and aspects of social participation. Sometimes these latter activities are referred to as Instrumental Activities of Daily Life (IADLs) to distinguish them from basic ADLs.

There are some situations where a narrowly-focused ADL assessment is used to allocate benefits related to a wider range of needs. For example, the ADL assessment may include consideration of whether a person can move within the home (the ‘transfer’ ADL), but not external mobility, while the benefit provided notionally covers mobility outside the home as well as within it. We can see that an ADL assessment may be used to categorise people as disabled (or severely disabled) without the assessment having such a natural connection with the needs that are to be met as we might imagine at first sight. The assessment may seek indicators of needs rather than identifying the exact needs to be met.

A striking example of an explicitly ‘indicative’ approach is the ‘cooking test’ used to ascertain eligibility for the lower rate care component of Disability Living Allowance (DLA) in the UK. The test examines whether a person can cook a main meal for one person on a traditional cooker. The test encompasses elements such as planning the meal, preparing vegetables, coping with hot pans and knowing whether the food is cooked properly. The test is not affected by whether the person used to cook or wants to cook; it is also assumed that those who do not know how to cook are willing to learn. A person who normally ate microwaved convenience food could still be found to be in need of assistance by failing the cooking test, if he or she was not capable of preparing a main meal. Furthermore, there is no expectation that the cash benefit provided will be used to purchase help with preparing meals or to meet the extra cost of pre-prepared meals.

More generally, provision of assistance in cash opens up the possibility that the cash will be used for other purposes than to purchase assistance with the assessed ADLs. A person who has grave difficulty dressing and eating may be awarded a benefit in the expectation that he or she will purchase help with these activities, but the person may nonetheless choose to struggle through dressing and eating unaided and use the money for something else. This scenario raises rather fundamental questions. On one side, the principle of autonomy suggests that the person should be able to use the money in accordance with his or her preferences. On the

other, failure to spend the money on care might be taken to imply that the initial assessment of care needs was incorrect and the money should be withdrawn.

This issue has arisen in various ways in a number of states, and various solutions and compromises have been adopted. Some states have a 'laissez faire' approach, accepting individual autonomy, although it is arguable that this tends to be connected with an inadequate level of benefits. For example, in Austria the assessment for care insurance is based on a rubric setting out specific care activities with corresponding allocations of time. However, it is recognised that the cash provided for each level of care would generally not purchase the time required to undertake exactly the level and type of care specified in the assessment. In Germany, care insurance recipients can choose between a package of services and provision in cash, with the latter having a considerably lower value than the notional costing of the service provision. The cash option is very popular. Some commentators interpret this as an adverse reflection on the quality of services provided; others point to the possibility that the cash is not used to purchase care, but is diverted to other purposes. However, a carer must be nominated by those taking up the cash option, and there is provision for checking up on the nominees.

Other states have tried to bring the disabled person's preferences into the process of assessment and provision in an attempt to reconcile autonomy and administrative control. For example, in the provision of direct payments by the Flemish Fund (Belgium), the applicant's degree of disability is assessed using ADL scales along with other information about impairment. This information is used to place the applicant in a budget category. Then an assistance plan is developed which is meant to allow the disabled person to indicate how he or she wants to organise his/her life. The Scandinavian states have also adopted various measures along these lines, for example giving the disabled person the position of employer of the carer, with rights to specify what care is provided and by whom.

#### *Non-Disability Criteria in the Allocation of Assistance with ADLs*

We have already noted that the provision of assistance with ADLs may be affected by other statuses, notably qualification for certain types of pension. There are two other main criteria which may affect the allocation of assistance. Assistance may be subject to means tests, and there may be age limits on assistance. It is not our aim here to give a comprehensive overview of provisions which describes all their categorical (disability-related) and non-categorical rules. Our interest is in how the presence of means tests or age limits may reflect conceptions of disability and influence the operation of disability assessments.

We begin with the issue of age limits. There are abundant examples where the designation 'disabled' is restricted to people under a certain age, often 65 (usually the designation can only begin under age 65 although once obtained it continues thereafter). For example, in Denmark the rights specified by the Law on Social Services relating to mobility, social contact and the development of skills are age-limited. In the UK, people under 65 may qualify for both care and mobility elements in DLA, whereas provision for those over 65 is confined to the care element. In some states, the needs of elderly people are covered to a lesser extent than the needs of the younger disabled, not by expressly differentiating the range of needs envisaged, but simply by providing a lower level of benefit. This is the case, for example, for certain benefits in France and Belgium.

One explanation of these differences is that expectations about the range of normal activities which constitute activities of daily life depend on age. Specifically, people over 65 may be expected not to be working, which reduces their need for mobility assistance. Some states explicitly envisage higher levels of provision for people who are working, reflecting the cost of activities associated with work (such as travel). In Denmark, provisions under the Law on Social Services are oriented towards the most active; there are separate, and less generous, provisions for pensioners under the Law on Social Pensions. In the Netherlands, there is no age limit, but mobility needs are evaluated on a case-by-case basis, which may allow differential social norms for younger and older people to be incorporated into the assessment. Separate provisions for those of working age and the elderly were recently brought together with the introduction of WVG in the Netherlands, a move viewed with some reservations by interest groups representing the disabled (van Ewijk and Kelder, 1999, p.27). Their concern is that the demands of the elderly will reduce the resources available for younger disabled people. This fear is given some credence by the situation under the Finnish Law on Social Services, where there are no age limits and there has been criticism of the substantial share of resources which goes on providing transport to the elderly.

A somewhat different rationale for age discrimination comes from the 'complete life view' of equality. On this view, treating the old differently to the young has no moral significance if all persons are treated the same when they are young and when they are old (Daniels, 1991). By contrast, uncompensated disability results in the disabled person having lower welfare than the fully-able on a complete life view. On this perspective, it is important to distinguish between needs arising from 'normal' aging (which are expected to be broadly equal across all, and therefore do not call for compensation) and needs arising from exceptional conditions which can be designated 'disabilities'.

It must be noted that there is by no means general acceptance of the principle of taking a complete life view, and there are counter-arguments for treating people with dignity and respect at every point in their lives. Nonetheless, elements of the distinction between normal and exceptional conditions can be found in the concepts of disability used in European states. A distinction between normal aging and disability may be made by using medical indicators such as illness and impairment. For example, assessment for the ACTP for people of working age in France involves two stages, a medical assessment of disability and a needs assessment. Assessment for PSD for the elderly is subject to a needs assessment only. Conversely, in the Irish debate on care allowances (discussed further below), the government has pointed to the difficulty of distinguishing between the disabled and the frail elderly as a reason for not removing the means test on the Carers Allowance.

In some systems, the operation of age limits is linked to the use of means tests, with provision for the elderly being more often subject to means tests. Again, the idea of a complete life view may be invoked to rationalise this structure. Whereas policy for the disabled may aim to raise the welfare of disabled people to the level which might have been achieved in the absence of disability, policy for the elderly may be directed to the more modest target of ensuring an acceptable minimum standard of living for all. This is broadly the situation in Sweden. The national report for Sweden suggests that there is considerable pressure to qualify as disabled in order to benefit from non-means-tested measures, and the local authorities have responded to this by making increasing use of medical certification. One important implication of this

argument is that it is necessary to delve very deeply before drawing a conclusion about whether an assessment is highly ‘medicalised’ or not. The Swedish Social Services Law is quite explicit in giving a non-medical account of disability in its general definition of the target group, but this does not necessarily exclude the use of medical information by assessors on the ground faced with allocating limited resources across people with similar needs.

One of the most explicit illustrations of the relationship between the medical assessment of disability and means testing can be found in the current debate in Ireland over the means-tested Carer’s Allowance. Much of the debate about caring in Ireland has revolved around payments to carers, and one of the main aims of campaigners is to reduce or remove the means test on the Carer’s Allowance. Several reports and debates have linked the removal of the means test to the establishment of clearer criteria for determining who counts as a person in need of care. The Minister of Social, Community and Family Affairs has argued that his Department is not equipped to undertake detailed individual needs assessments and that this is a function more appropriate for Health Boards. The Department’s view is that the primary purpose of social security benefits should be income support rather than the financing of a care system.

We can see in these examples that non-categorical provision, subject to means- and needs-testing, may be an alternative to classification as disabled, in the sense that non-categorical criteria may render the categorical criteria redundant, or at least less important. It is widely held in social policy that non-means-tested, categorical provision is superior to means-tested, non-categorical provision. However, this does require that categories are defined in a meaningful way which does not result in arbitrary distinctions between people with similar needs. The wider the range of needs covered by provisions for assistance with ADLs and IADLs, the more difficult boundary problems arise. People may have difficulty with IADLs for reasons which cannot be directly attributed to an identifiable medical condition. Difficulties performing some household tasks may be due to failure to acquire the relevant skills or lack of motivation. Transport difficulties may affect fully fit people because of poor infrastructure or lack of money. The fact that needs assessments are often age-differentiated indicates that a definition of disability does not flow naturally from the needs revealed by enquiring into these areas of life. Those who do not enjoy the full range of rights, more widely defined, may include people who are socially isolated due to age or other barriers which are not clearly a consequence of their physical or mental condition.

### **3.2 Income Maintenance and Income Support**

#### *Definitions of Disability*

All the states covered in this research have cash benefits for people who are unable to work due to disability. Many states have two benefits: a contributory insurance benefit which provides a flat-rate or earnings-related benefit, and a non-contributory benefit which provides basic income support, which may or may not be means-tested. The first criterion for establishing eligibility for these benefits is that the person is not working. Small exceptions are found in most states: therapeutic work may be permitted or work for only a few hours per week. Some states, including the Netherlands, Sweden and Germany, have a concept of partial disability which is consistent with regular part-time work. In practice, few recipients of partial benefits do in fact work, so the system operates more as a way of awarding lower benefits to less

severely disabled people (if household income is sufficiently low as a result, benefits may be supplemented with social assistance).

The definitions of disability used for these benefits are based on lack or loss of work capacity or earning capacity. The appropriateness of these definitions depends on whether plausible connections can be made between work capacity and health status. Since claimants are usually not working, the central issue for assessors is to establish whether the applicant's non-employment is because of the state of his or her health or for some other reason (general labour market conditions, low skills, lack of motivation, etc).

There are broadly three approaches to answering this question adopted in the European states. One approach is to go through a procedure for examining the reasons why a person stopped working and identifying the obstacles to the person resuming the previous job. We refer to this as a 'procedural' approach. A second approach is to focus on the reasons why a person is not able to take up work, by comparing his or her capacities with the demands of the labour market. We refer to this as a 'capacity profile' approach. The third approach is to evaluate disability without explicit reference either to previous work or to possible work, but instead to examine the extent to which a person's functioning is impaired. This is referred to below as an 'impairment-based' approach.

#### Procedural approaches

In a number of states, inability to work is evaluated by going through a process in which options for medical and/or vocational rehabilitation, and other routes to a return to work, are explored. In this context, the designation of a person as disabled signifies the end of this process. In the intervening stages, the person may be classified as sick or as a 'rehabilitant'. The process may start with an investigation of the scope for adapting the person's previous job, or placing the person with the same employer in a different job, in the first instance. The procedural approach is most relevant to insurance systems, particularly those where entry onto disability benefits is through the route of initial receipt of short-term sickness benefits.

An example of an explicitly procedural approach is the Swedish 'step-by-step' process. In this process, the potential for resumption of the previous job, with or without rehabilitation, is explored first, followed by consideration of other possible jobs with the same employer, and then of other job options with or without rehabilitation. Other states are not so explicit, but an implicit process may be created, for example by rules requiring the administration to consider 'rehabilitation before pension' as in Germany.

One of the features of the procedural approach is that clear decision rules for determining disability are often lacking. A lot of information may be gathered about the person's condition and capacities; rehabilitation services in particular often use detailed assessment instruments. These are used to assess a person's work capacity in order to guide him or her to a new occupation, and identify any training and assistive requirements for entering the occupation. Generally they are not designed to determine thresholds for disability assessments.

The procedural approach may also involve considering job possibilities by using databases which identify work suitable for a person's remaining capacities. In the administration of EMR in Germany, the assessor uses a schedule which highlights a variety of aspects of working life:

whether the person can do heavy or only light work, whether he or she can stand, sit, or walk all or some of the time, etc. The assessment also considers the person's medical/ psychological ability to deal with work requiring concentration, adaptiveness, flexibility, responsibility, contact with the public, etc., and indicates conditions which would be dangerous to the person: dampness, draughts, temperature variations, factors leading to allergic responses, noise, frequently changing times of work. However, the scheme for EMR does not have clear decision rules indicating the thresholds between incapacity and capacity to work. A high level of individual judgment and discretion is used in deciding on an appropriate course of action for the person being assessed; this may involve negotiation with the person over an appropriate rehabilitation plan.

In states where the institutional linkages between the social security and health care systems are strong (where the same insurance fund finances cash benefits and health care services), we find that detailed medical investigations of a person's condition are often undertaken, partly to verify the condition but partly to ensure that appropriate medical rehabilitation is available. In the Scandinavian countries, by contrast, the social security administration does not undertake detailed medical enquiries, relying instead on the report provided by the claimant's own doctor. There is also more emphasis on vocational than medical rehabilitation in these countries (although the borderline between the two types of measure is not necessarily clear in practice).

One question about the procedural approaches which is difficult to answer clearly is whether a person who reaches the end of the process without returning to work must necessarily be classified as 'disabled'. Another way of putting this question is to ask how much flexibility institutions have to determine at some stage that the person's main obstacle to resuming employment is not disability. Such a finding could imply that the person should be reclassified as unemployed. This possibility exists in principle in all the states, but in practice its use can be constrained by the assignment of institutional responsibilities. Where unemployment benefits and services are separately administered, the unemployment institutions may resist taking on responsibility for paying benefits to people who they regard as only marginally employable. The converse can also happen: disability insurers may reject applications from people who have been unemployed. One result may be that people stay where they started: a person whose claim begins with sickness takes the 'disability path' whereas one whose claim begins with unemployment takes the unemployment path.

However, it should also be noted that, if the person does not resume work, the sickness and rehabilitation process does not have to end with disability. Another option is available which is heavily used in some states: the process may end with retirement. The process itself takes time, and various mixed disability-retirement options may be available for older workers who have been out of work for some time. Institutional linkages between disability and old age insurance also facilitate the use of these mixed options. A number of states have provisions for early retirement in which health limitations figure, placing them on the borderline of the categories of disability and old age. For example, in Finland, there is a provision for early retirement whereby older workers (58-60 depending on year of birth) may draw both national and employee pensions if there is lowered working capacity on the basis of a combination of factors, including sickness, impairment and injury. There must be a medical diagnosis but it is not necessary to establish its dominant causal role in explaining a person's limited earning capacity relative to other factors such as education, redundancy of skills etc. In addition, early

retirement is possible from age 60 (without medical indications) and a part-time pension can be drawn from age 58 with evidence of reduced earnings. In France, for those becoming unable to work when over 60, a form of health-related early retirement is available (many people with a full contribution record can retire at 60 in any case). The conditions for *une retraite anticipée pour inaptitude au travail* are loss of at least 50% of work capacity, and (for those working at the time) a determination that continuation of work would endanger the person's health. Note that this benefit refers to inability to do the current/ previous job (inaptitude) rather than the general concept of incapacity used in the award of long-term invalidity benefits.

### Capacity profile approaches

In some states, disability is evaluated by taking a 'snapshot' of a person's work capacity at a specified point, for example after the designated sickness benefit period ends. The states which take this approach include the UK, the Netherlands and Ireland. A feature of these systems, particularly the UK and the Netherlands, is the way that instruments of assessment are used which endeavour to define clearly the threshold for work incapacity. These approaches are often seen as establishing a more rigorous test of disability than procedural approaches, which generally start from reference to the person's previous job. Capacity profile approaches are certainly more abstract than procedural ones, as the detailed discussion below of the examples of the UK and the Netherlands shows. In some states, it is more or less explicit that a procedural approach is applied to people who have been working and a capacity profile approach to people without a recent work history. The national report for Finland notes that the latter group of people who enter the disability assessment system from unemployment are '[e]specially problematic cases.. whose working capacity is assessed in a most abstract way.. [as they are] presumed to accept a very large range of job offers'.

The basic idea of a work capacity assessment is that a person's capacity is described and compared with criteria about the capacities needed to engage in paid work. The UK and the Netherlands do this in quite different ways. Both begin by assessing the person's capacity. The UK's 'Personal Capability Assessment' (PCA) consists of 14 basic activities such as walking, climbing stairs, sitting etc. (The Irish Medical Review and Assessment process uses a very similar list.) In the Netherlands, physicians use a standardised approach for measuring a claimant's functional ability to perform work, which defines 28 different types of action required in different occupations, including the basic activities in the PCA but also more specialised work-related activities such as tolerance of environmental conditions (reactions to heat, dryness etc), tolerance of vibration, ability to use special tools on the body (e.g. masks) and so on. Whereas the UK and Ireland have a mental health assessment schedule which is separate to the PCA, the Dutch assessment includes some psychological criteria (ability to work with others, tolerate stress etc).

In the Netherlands, the results of the capacity assessment are explicitly compared with the capacities required in particular jobs, which are specified on a database (FIS). FIS contains descriptions of thousands of jobs existing in the Dutch labour market, with information on the functional capacity demands of the job expressed in terms of the 28-point assessment, as well as other information such as work pattern (shifts, hours etc), wages, job level (a general indicator ranging from 'unskilled' to 'scientific'), job requirements: education, experience, nature of skills required (managerial, technical, verbal..) and so on. Data in FIS are matched with the person's capacity assessment to ascertain what jobs he or she might still be able to do.

By comparing potential earnings from jobs identified using FIS with the person's previous earnings, the percentage loss in earning capacity can be determined.

The way in which the UK PCA is compared with the requirements of paid work is quite different. In the UK, the impact of a person's limitations is not judged in the context of specific work situations. Each of the listed capabilities is accompanied by several descriptors, and each descriptor carries a specified number of points. The decision about whether the person is capable of work depends on the total number of points accumulated. Many of the descriptors for the capability assessment refer to everyday activities (e.g. turning a tap). This is an important feature of the UK rules as it means that assessors do not have to consider the requirements of specific jobs, nor do they have to indicate what job a person judged 'capable' might actually do. It should also be noted that the UK has no partial incapacity benefit, so a person can only be judged 'capable' or 'incapable'. The requirements of the person's last job do not come into the assessment, and the extent of earnings loss is not measured.

As noted above, the Irish system contains much the same list of capabilities as in the UK, but Ireland maintains a further work capacity assessment which is more open and discretionary than the Dutch and British systems. Despite the institutional effort invested in the development of FIS, it is acknowledged that the system does not capture all the elements of a good match between a person and a job from which earning capacity can be predicted. In the UK, it is arguable that the PCA does not attempt to predict a person's job prospects, but instead indicates whether a person should be required to seek work. Administrative guidance often uses the formulation that the person should be 'treated as incapable of work' rather than suggesting that he or she really is incapable of work. This distinction has become more evident with recent reforms which invite disabled people to take up job-seeking advice while still treating them as incapable of work for benefit purposes.

#### Impairment-based approaches

Perhaps the best-known instruments for disability assessment are impairment tables or baremas. These have a long history. The earliest baremas attached percentage ratings to physical damage from war or industrial injuries (5% for loss of a finger, 50% for loss of a leg..). Modern baremas include ratings for the damage from disease and internal injuries, sometimes measured using innovative medical technologies. The tables are divided into chapters based on physical or mental components of the body or body systems and contain guides to medical benchmarks of normal condition. Measurements such as flexion of joints, respiratory displacement, blood pressure and circulation are used to establish the benchmarks. The rubrics have a distinctive language. Terms like emaciation, deficiency, deformity, anomaly and abnormality recur, and the subjects are the body's component parts: heart, lungs, other internal organs, parts of the skeletal structure and so on. Since impairment is assessed in 'parts', the overall level of impairment may be the product of impairment ratings for several different parts of the body. One of the signals of an impairment-based rubric is the existence of rules or tables for combining the body part ratings into an overall rating for the person.

'Classical' baremas assess the degree of disability directly from the description of a person's medical condition in terms of impairment. For example, degrees of loss of sight or hearing, measured using accepted technical equipment, may be translated directly into a degree of disability. This can be called a 'direct measurement' approach. However, in practice, it is

difficult to rate the severity of a person's impairments without implicitly considering their consequences for important life activities such as work. Thus many baremas do not rely entirely on direct measurement, but also allow consideration of 'disabling effects'. For any given impairment, the doctor may select from a range of values which reflect differences in the impact of the condition on a person's life. In some cases, the 'disabling effects' approach provides methods for measuring severity which avoid some of the limitations of technical measures. For example, a respiratory condition may be described in terms of its effect on a person's mobility rather than in terms of the displacement of air from the lungs.

One of the difficulties in describing impairment rubrics is that they often adopt a mixture of 'direct measurement' and 'disabling effects' approaches. Matheson et al (2000) have analysed how the Guides to the Evaluation of Permanent Impairment, developed by the American Medical Association and often referred to in this field, adopt different 'levels of measurement' between chapters and even within chapters, ranging from 'observed signs and reported symptoms' to 'inability to perform specific work behaviours'. We find this mixture of approaches in several of the baremas used in European states. For example, the Spanish Guide 'Valoracion de las situaciones de minusvalia' (VM) uses a direct measurement approach to the evaluation of musculo-skeletal impairments but includes disabling effects in other chapters. In the chapter on mental illness, the class of disability is made up of three components: effect on daily life, effect on work capacity, and a third category reflecting the severity of the diagnosis. The discussion of the latter category notes that a given diagnosis may be accompanied by quite different degrees of dysfunction, and emphasises the issues involved in identifying sufficient deviation from the norm for the person to be classed as mentally ill.

Mental health problems necessarily manifest themselves as limitations in a person's ability to do certain things: as limitations in capacity. Even if an impairment is known to exist (e.g. the person has some observable brain abnormality or damage), meaningful measures of severity will look at effects on capacity. However, this is not just true for the special case of mental health. In practice, the degree of severity of an impairment is often measured by looking at its disabling effects. In the barema used by the COTOREPs in France, the extent to which an impairment is deemed severe is explicitly evaluated by looking at its effect on (dis)ability. (Exceptions are sensory impairments, which are evaluated directly.) The consequences of impairments are described in terms of spheres of autonomy, such as coherence (person is able to converse and comport him/herself in a logical and intelligible manner), orientation (person knows the time, intervals in the day, and place), personal hygiene, dressing etc.

Both the Spanish VM and the COTOREP barema are applied outside the area of insurance-based income maintenance benefits, often to people who have never worked. They contain little explicit consideration of the demands of the labour market and no guidance on how the person's previous occupation might affect the assessment. By contrast, when insurance bodies use an impairment-based approach, they may develop extended protocols for describing the disabling effect of impairments in terms of the person's ability to do particular jobs, and the protocols may give different values of disability for different areas of employment.

In Portugal and Greece, the impairment tables used by the insurance institutions are documents with the status of law. Through legislation, the government has sought to establish a consistent approach to disability determination which applies to private as well as state bodies, and is

referred to in the resolution of disputes by courts. The tables can be understood as an attempt to reduce transaction costs around disability determination and to impose consistency on diverse actors, although in practice there is considerable flexibility in applying the tables. A similar desire to cut short potentially-attenuated negotiations with the aid of impairment tables, even though they are admittedly somewhat arbitrary, is remarked on in the discussion of IIOD in the Belgian national report, and this motive may also lie behind the widespread use of impairment tables in the private sector in other states.

From this perspective, impairment tables function as a regulatory instrument for resolving disputes over compensation between parties who are equal in the sense that one (the insurer) does not have the authority and legitimacy to impose a settlement on the other (the disabled person). While the case may not in the end go to Court, the possibility of a judicial resolution is open and colours the strategies of the parties. Of course appeals to judicial-type institutions are also available to disabled people in the process-based and work incapacity-based systems discussed above, but it is arguable that these systems tend to have developed more authority and legitimacy to achieve settlements without disputes and appeals. We suggest that institutions using impairment tables tend to have less well-developed structures of governance and less accountability than those using the process-oriented and work incapacity approaches. We discuss this issue further in chapter 4.

In Italy and Spain, the insurance institutions are not subject to a legally-imposed *barema* and they have developed their own assessment instruments, built on an impairment-oriented approach. The instruments are developed by doctors working within the institutions. The Italian report draws attention to the way in which the INPS has developed its ‘technical discretionary power’ through the preparation of protocols. A body of technical knowledge is developed (and written up, and used in training) which links medical data on diagnosis and impairment to specific limitations in work or daily life. The INPS has established a number of guidelines related to specific conditions, along with a standard form for the legal medical report. Advocates of this approach see the protocols as technical instruments rather than as policy documents, and point to their usefulness in enhancing the consistency of decision-making across offices and regions. Critics argue that disability assessment is not just a technical medical matter, and that the instruments do not have legitimacy if they are not brought under a wider political purview and subjected to criticism and debate.

Thus the process of development of assessment instruments can itself be seen as a domain in which different professional groups exercise power, and the dominance of doctors in development and revision processes in some states is evident. Some schemes are developed internally in administering organisations and are not readily available to the public. By contrast, the development of the PCA in the UK involved a wide range of participants, including medical and other professionals, disabled people, and representatives of organisations of and for disabled people. (It is striking, however, that consultation has not brought consensus: the operation of the PCA is highly contested and criticised.)

To some extent, the approaches discussed in this section overlap with the process-based approaches discussed above. For example, insurance institutions in Germany and Austria also invest considerable resources in developing their technical discretionary power in the form of detailed guides and protocols, and the personnel involved are entirely medical. However,

Spain, Portugal, Italy and Greece differ from Germany, Austria, France and Belgium in the degree of separation of cash benefit provision from the health service and the virtual absence of rehabilitation services linked to cash benefit provision in the former states. All these states differ in turn from Sweden, Norway and Finland in the dominance of doctors in the insurance system and the relatively heavy emphasis put on medical diagnosis and medical data in the former states. (Denmark is in a category of its own as it lacks a disability insurance system; as the discussion below shows, it exhibits an even less medical orientation than its neighbours.)

#### *Non-Disability Criteria in Income Maintenance and Income Support*

The discussion so far has mainly referred to the assessment of incapacity for work for the purpose of awarding insurance benefits. The contribution requirements of these benefits ensure that many of those being assessed have a work history, and that they tend to be older workers. However, contribution requirements vary widely between states. There may be some correlation between the 'height' of contribution requirements and the use of a previous work test of incapacity (e.g. Spain and Italy have high requirements and use a previous work test; the Netherlands and the UK have low contribution requirements and use a general labour market test), but we do not have the data to test this hypothesis fully.

Given that not working is the primary criterion for receiving a disability income maintenance benefit, it is possible to imagine a non-categorical approach where anyone not working would receive a benefit, regardless of whether the cause was unemployment, disability or another factor such as care obligations. Across the European states, we find that a non-categorical approach is sometimes adopted in the area of means-tested (assistance) benefits, but never in insurance benefits. One explanation is that the distinction between disability and unemployment is critical to the allocation of responsibilities across insurance institutions which may have quite separate administrative and funding structures. This fragmentation is more the rule than the exception in Europe. Even in the Scandinavian states, usually thought of as having integrated approaches to social policy, with central government providing a high degree of unification in both policy formulation and funding, the unemployment insurance providers are institutionally separate to the disability benefit system. The Netherlands also has separate institutional structures, although reforms over the last 20 years have brought considerably more policy coordination to the insurance system. It is arguable that there is a trend towards more integration, as central governments challenge the traditional policy autonomy of some social insurance bodies in an effort to grapple with fiscal imbalances. Nonetheless, the institutional barriers to a noncategorical approach are considerable.

The UK and Ireland provide examples where there is no institutional obstacle to a noncategorical approach but the disability category is nevertheless maintained. As discussed above, the category distinction may be used to determine what administrative rules and requirements are deemed appropriate for the benefit recipient, but changes in policy towards promoting employment among disabled people have destabilised this distinction in the UK.

In some states, the insurance system is fragmented but the assistance system is integrated. In Denmark, there is no disability insurance system (except for industrial injuries and occupational disease insurance, which is semi-private) and income support for disabled people is integrated with general social assistance. This has contributed to some striking innovations in the way in which the disability category is used in income maintenance policy in Denmark.

The lowest level of disability pension may be awarded when the claimant's working ability has been reduced by at least half for medical *and/or social* reasons. Where the award is for social reasons, the benefit awarded (specifically, the means test) is aligned with general social assistance. Higher levels of pension are currently awarded based on higher levels of work ability reduction (indicated by more severe functional limitations). However, the rationale for these distinctions has been somewhat unclear. One rationale is that more severely disabled people have higher living costs arising from their disabilities, so benefits should rise with severity. However, it is arguable that, if the purpose of the categorical distinction is to reflect extra costs of living, then the assessment of disability should focus on these extra costs, and not on inability to work. This idea is behind Danish reforms which are currently in progress. From 2003, the income support and activation system will focus solely on 'working ability', a concept which refers to any obstacle to working and is not medically-based. Needs related to medical disability such as assistance with ADLs or other aspects of independent living will be reflected in separate provisions under the Social Service Law, rather than being incorporated into the main income support benefits.

An important example of a non-categorical social assistance system is Germany's *Sozialhilfe*. Individualised assessment is a central principle in the administration of *sozialhilfe*, and this arguably means that differences between people in their needs for assistance with ADLs and other forms of 'integration assistance' can be reflected in each individual's assessment. However, individualised assessment is administratively costly, and may also be seen as excessively discretionary. *Sozialhilfe* is explicitly designed as a residual benefit, and increases in the number of recipients may create pressures for a more categorical approach.

It is possible that if general means-tested benefits were more widely available and more securely funded, the need for separate categorical disability benefits would be reduced. This possibility has been discussed most intensively in France, where there is a general social assistance benefit (RMI) as well as an assistance measure for disabled people (AAH). Both are means-tested, but AAH is more generous (particularly to single people) and the means test is less stringent. When RMI was introduced (in 1988) there was a debate about the purposes of the distinctions made in awarding AAH (which was already in existence). The issue has recently been re-opened by a new law which came into force in January 2002, concerning access to services provided by training and rehabilitation institutions. The law classifies both the long-term unemployed and the disabled as 'vulnerable'. This measure reflects the development of a new conception of unemployment which sees the problem not as 'loss of a job' but as 'distance from a job'. This development has again opened the question of the relationship between RMI and AAH, especially as research suggests that many people receiving RMI have some limiting health condition.

More generally, social assistance schemes may absorb people with minor disabilities and thereby reduce pressure on disability benefits 'proper'. Conversely, there is intense pressure from needy people to establish the status of disabled in the states which do not have any general social assistance or where provision is subject to local budget constraints and/or is highly discretionary (particularly in Greece, Italy, Spain and Portugal).

### 3.3 Employment provisions

The simple scheme offered by Mashaw and Reno with which we introduced this part of the report suggests that the definition of disability used to allocate access to vocational rehabilitation (VR) services should focus on the person's need for, and likely benefit from, these services. As in the example of assistance with ADLs, there seems to be a natural connection between rehabilitation and health status which supports this approach. Rehabilitation is not needed by, or of benefit to, people who do not have relevant health problems.

However, in analysing the definitions used in employment provisions in member states, the picture is not quite so straightforward. While rehabilitation may be naturally linked to disability, many provisions for training are of potential value to a wider range of people who face obstacles entering employment which may or may not be related to a health limitation. For example, the Employment Service (ES) may provide living allowances for people undertaking training, and these may be paid for a longer duration for those designated as 'disabled' than for others. Subsidies may be paid to employers who take on different categories of workers who face obstacles entering employment; these may be paid at different rates or durations for different categories (e.g. one rate for the long-term unemployed and another for the disabled).

Another important area of disability employment policy in the member states is the operation of quotas, which may also bring with them revenue from non-compliance levies which is allocated to institutions specifically charged with promoting employment among disabled people. As we show in the following discussion, there is some ambiguity about whether the relevant definition of disability for a quota should focus on a person's limitations and the difficulties these raise in obtaining employment, or whether the quota is intended as an anti-discrimination policy, in which case the criteria for a relevant definition are different.

In the following discussion, we divide the employment policies of the European states into three groups: specific disability-related interventions (including rehabilitation programmes) which we see as being largely self-targeting, often to people with particular impairments; general employment measures such as training allowances, subsidies and placement assistance, and quota schemes. We show that each area raises separate issues about the relevant definition of disability and the relationship between disability and other obstacles to entering and maintaining employment.

#### *Specific Disability-Related Interventions*

The measures which we include under this heading are rehabilitation services, sheltered workshops and adaptations to workplaces. Across the states covered in this study, there is a huge variety of measures falling into these categories. Some are linked to the social insurance system, some to social services, and some draw heavily on voluntary and charitable endeavours. Often provisions are impairment-oriented: there may be specific measures for people who are blind or deaf, for example. One result is that providers often use an impairment-based definition of disability to allocate their services, although their understanding of the nature and consequences of disability may not be impairment-based (cf. the discussion of 'definitions' in chapter 1). In social services provision, people may come into

the ambit of disability-related services through specific pathways (e.g. referrals from medical services) with the result that assessments of disability are not routinely required and definitions may not be clearly established. Service providers may not necessarily be engaged in an intensive process of policing boundaries in order to ration resources: on the contrary, there may be concern that disabled people are not being reached. In such conditions assessments may focus on gaining an understanding of a person's needs rather than establishing whether he or she is entitled to services.

There are, however, some circumstances in which a general assessment of disability is made before allocating a specific disability-oriented measure. In the states which have disability registration or general assessment systems (e.g. Germany, Austria and Spain), people must usually be on the register, or have achieved a certain percentage of disability in the general assessment, in order to be eligible for sheltered workshop places or similar measures. These systems are discussed in more detail below in the section on quotas.

Another situation where a general assessment might be made is where workplace accommodations are needed and the allocation of financial responsibility depends on the person's disability status. For example, employers may be liable to ensure a safe and appropriate working environment for workers generally, while being able to obtain specific financial assistance for workplace adaptations if the worker is disabled. The funding authority may consider not only the worker's need for the adaptation, but also whether the worker's general level of functioning is sufficiently limited to justify public financial involvement. The claim might be rejected if, for example, the worker needs an expensive adaptation to do a particular highly-specialised task, but is not generally disabled and so can do other tasks without assistance (this issue is discussed further in chapter 5).

#### *General Employment Services*

Compared with specific disability-related measures, general employment services are potentially valuable to people who have no health limitation. In some states, employment services focus their efforts on a group designated as 'hard to place'. One of the main ways in which the hard-to-place are identified is by experience: if a person has been unemployed for a certain duration, this indicates the need for extra resources. However, waiting for the hard-to-place to reveal themselves is not ideal, and employment services may also look for indicators of risk of long-term unemployment, such as low educational status or health-related disadvantages.

We therefore find that special services and additional resources may be allocated on the basis of disability within such systems. Such measures are often closely linked to mainstream provision for the unemployed. Unemployment itself is the first element in access to measures, and the primary indicator of disadvantage. Assessment of people as disabled within this group may be used either to allocate special measures or to enable measures normally restricted to the long-term unemployed to be made available more quickly. Health status is used as an indicator of the likelihood that a person will prove to be hard to place, and assessments focus on capacity limitations which affect employability. Impairments which do not necessarily restrict employability do not call forth any special measures.

Examples of provisions where the primary orientation is towards the hard-to-place are

measures under the Labour Market Service Act (AMSG) in Austria and the Law on Employment Services in Finland. The Finnish report raises a number of issues about the relationship between the disabled and other groups in employment policy. For some years, the disabled were the sole 'special' group in employment service provision, but recently the focus of Employment Service activity has shifted to other groups such as the long-term unemployed and the young unemployed. Resources are more thinly spread and the advantages of being recognised as disabled are sometimes questionable.

Recognition that the relationship between a given impairment and ability to work may be affected by a range of confounding factors (success of medical interventions, availability of aids, other skills of the person etc) may lead administrators, whose main concern is work placement, to concentrate less on impairments and more on contextual factors in assessing degrees of disability for employment policy purposes. At the limit, employment provisions may be 'mainstreamed' so that access to employment programmes does not depend on classification as disabled, but instead arises from a disadvantageous labour market position, however caused. On one hand, mainstreaming avoids the problem of defining disability but, on the other hand, it may lead resources to be diverted away from those with severe disabilities, or from those with physical disabilities towards those with problems of social adjustment (Bengtsson, 1995).

The Swedish report highlights the converse set of issues. A considerably wider repertoire of subsidies and other measures is available to those recognised as disabled by the Employment Service (ES). A report from the National Audit Office has suggested that offices are increasingly classifying the hard-to-place as occupationally disabled, to enable them to utilise these measures.

These examples indicate some of the difficulties in finding relevant definitions of disability in employment policy. In the Swedish case, the implicit definitions used are relevant in the sense that a person may be designated as disabled in order to enable him or her to access suitable measures. However, from the perspective of the funding authorities, there is a danger that resources intended for those with the most severe disadvantages are diverted to less-disabled people. This implies that it would be desirable to monitor how the ES helps disabled people by using a definition of disability which is not under ES control.

The difficulty with this idea is that it is hard to see how an external definition could be constructed which is relevant to the underlying criterion of how hard a person is to place, as this will depend on many contingent factors. It is conceivable, for example, that a well-educated wheelchair user might, in some settings, be easier to place than someone who is physically fit but unskilled.

This problem also arises in the administration of subsidy schemes, where there is a risk that money will be wasted subsidising people with disabilities who are fully productive in their particular jobs. In the Belgian CAO-26 scheme (a collective wage agreement scheme), a labour inspector reviews the person's performance on the job and may conclude that the person's productivity is insufficiently impaired to qualify for a subsidy even if there has been a general assessment of disability. By contrast, the Flemish VIP (Vlaamse Inschakelingspremie) scheme provides a subsidy which depends on the person's general disability classification.

This is also the approach used in France, where subsidies for employees classified as ‘TH’ by the COTOREP depend on the general classification (A, B or C) rather than on an inspection of the person’s performance on the job. There would seem to be more risk of deadweight losses of subsidy in the latter type of scheme, but the CAO-26 scheme can be criticised as relying excessively on bargaining between the employer and the subsidy provider.

The general assessment of disability used in these schemes is usually based on an analysis of functional limitations. The underlying conceptual framework is therefore similar to that used in work incapacity assessments for income maintenance benefits (s.3.2 above). In the UK, Ireland and the Netherlands, previous qualification for income maintenance benefits is one of the main ways in which disabled people establish eligibility for employment measures. In Ireland, receipt of an income maintenance benefit used to be essential to obtaining help with living expenses when taking up training or community employment places, but recently a separate training allowance has been introduced.

### *Quota Schemes*

In Germany, Austria and Spain, the definition of disability for the purposes of the quota is based on an impairment rubric. The German and Austrian rubrics are largely based on ‘direct measurement’, whereas the Spanish VM contains analysis of ‘disabling effects’ (see s.3.2). We noted above that a person with functional limitations may be fully productive in a particular job which is a good match for his or her functional capacities. This situation seems even more likely to arise under an impairment-based approach, as some impairments may not affect relevant functional capacities significantly or at all. This is recognised by a number of commentators, and the impairment-based definition is sometimes defended on the grounds that it is intended to aid, not only people whose productivity is reduced, but also people who may be at risk of discrimination because of their impairment.

As is discussed further in chapter 5, the relevant definition of disability for anti-discrimination provisions depends on the conception of discrimination and equal treatment which underpins the policy. An anti-discrimination policy which seeks to protect people whose productivity is unimpaired may use a very broad definition of disability, encompassing people with minor impairments and people perceived as having limitations that they do not in fact have. However, such a broad definition of disability would not provide a meaningful basis for a quota. The quota must somehow be selective, but the process of selection then invites the criticism that, by identifying people as disabled, quotas are themselves a form of discriminatory treatment.

The problems which arise with assessing disability for quotas can be seen as a type of agency problem. The employer is the agent who implements the quota policy. The employer may have superior information about the severity of a disabled person’s limitations in specific relevant situations, and he or she has an incentive to ‘cream skim’ i.e. to select those disabled workers whose limitations are least disabling in the job in question. If the employer is misinformed or holds prejudices about particular disabilities, the problem of cream-skimming is converted into one of discrimination. The employer may favour workers whose conditions are most easily understood and arouse most sympathy (e.g. physical rather than mental disabilities). This type of principal-agent problem cannot be resolved by regulation: instead, the employer’s behaviour and strategies have to be addressed directly in order to bring about a

better alignment of employer behaviour with the aims of policy-makers.

Several states have adopted reforms to their quota systems which, arguably, address this agency problem by linking quota fulfilment to the adoption of management plans to promote the employment of disabled people and counter discriminatory employment practices. Both France and Germany have introduced policies in which the quota-enforcing institution works more closely with employers than in the traditional regulatory model, and compliance with the quota can then be seen as a way of monitoring the effectiveness of non-discrimination policies rather than as a regulatory measure which is effective in itself. Recent initiatives in Germany involve making more financial assistance available to employers (under rules that leave scope for negotiation) and encouraging a more pro-active and wide-ranging approach to placement of disabled workers. On the side of the disabled person, there is an increased emphasis on finding placements which reflect the person's aspirations and preferences. Similarly in France there has been an increased emphasis, since the mid-1990s, on getting employers to develop plans for integrating disabled workers and supporting these plans with negotiated funding. In Italy, where the employment service retains some powers to direct employers to take on a particular person for a notified job vacancy, more effort is now invested in developing a detailed profile of the applicant and improving the match between disabled people on the register and the jobs that come up.

While these types of reforms mean that quota administration is rendered more consistent with non-discriminatory practice, the question of how disabled people should be identified for a quota remains unresolved. Some of the impairment rubrics used have a long history and incorporate outdated medical assumptions and social attitudes, but it is not easy to formulate appropriate replacements. For example, the Austrian RSV is widely acknowledged to be outmoded, but it is seen by doctors as acceptable if used flexibly. There is little political motivation to reform the RSV, because it is recognised that any revision would be highly contentious and unlikely to satisfy all the interested parties.

## **Summary**

This chapter has reviewed the use of definitions of disability in income maintenance, employment measures, and assistance with ADLs. Its central theme is that, in each of these areas, disabled people are seen as having particular relevant needs. However, the exact nature of these needs, and their similarities and differences with the needs of other groups, are not always clearly defined.

Even when the purposes of a categorical distinction are clear, further issues remain about whether the assessment process implements categorical distinctions appropriately. The difficulty of drawing distinctions may mean that policy-makers leave considerable discretion to implementing agencies. We have shown that there is often an institutional aspect to the delineation of disability categories. In integrated social policy systems, it may be easier for policy-makers to ensure that categorical distinctions are relevant to social policy purposes.

Given the difficulties of defining disability, it might be thought desirable to eliminate disability categories whenever possible, and to meet the needs of disabled people through noncategorical

social policies. We have shown that there are examples of such policies in the areas of employment (measures for the 'hard-to-place'), income maintenance (noncategorical social assistance) and assistance with ADLs (where elderly and disabled people may be assessed in the same way). However, in all cases there are issues about whether the needs of disabled people are adequately recognised and receive a sufficient allocation of resources.

## ANALYSING DISABILITY ASSESSMENT PROCESSES

The previous chapter examined the definition of disability by focusing on the relevance of disability categories to various social policies. In this chapter, we discuss how individuals are assessed for membership of disability categories. The debate about ‘medical’ and ‘social’ models of disability raises issues about what conceptions of disability best secure the rights of disabled people. Traditional social policies are sometimes criticised for their medical orientation and the discretionary nature of their decision-making. Medicalisation and discretion are linked in criticisms of the professional power exercised by doctors in disability assessment processes.

Given the importance in current policy debates of the contrast between the medical and social models of disability, it would be very interesting to be able to classify approaches to assessment according to their degree of ‘medicalisation’. However, this is not a simple matter. Medical knowledge and skills are used in a wide variety of ways in disability assessment. The relationship between the medical community, disabled people and the wider community is a complex one. Doctors may act as advocates and defenders for their patients, but then they may find themselves having to act as judges, working under strict constraints about the basis for their decisions. Doctors may seek, or at least accept, discretionary power in the belief that they can judge a person’s situation accurately, but then find that they are challenged by their peers or by their patients and by non-medical disability advocates. Our country examples suggest that doctors are often asked to make judgments which are not strictly medical. For example, doctors may be asked to visit a person in the home and report on aspects of the social environment. Medical personnel may be asked to implement a non-medical model of disability, perhaps reflecting their role as trusted professionals in the community rather than their specialist skills.

We showed in chapter 3 that most states maintain several approaches to the definition of disability simultaneously in different areas of social policy. It is not generally possible to speak of disability determination in terms of national models. Different models are found in social insurance, social assistance, social service provision and employment policy. Furthermore, in each of these areas, there are cross-cutting issues about the nature of the social rights created in that sphere of policy. For example, many commentators see means-testing as antithetical to social rights, and one cannot speak of the nature of disability rights in social assistance without acknowledging this contextual factor. Insurance-based systems, by contrast, are generally seen in social policy as strengthening social rights through the principle of contribution. However, such systems accord rights to contributors rather than citizens at large, and a significant number of disabled people cannot exercise these rights. Provisions that are neither means-tested nor contributory (often referred to as ‘universal’ provisions), are often placed at the pinnacle of desirability in terms of rights, but, as noted in the previous chapter, universal systems bring with them a heavy emphasis on other principles of allocation, often involving the exercise of professional power, such as the delineation of a disability category.

Another approach to rights is to examine whether and how rights enable a person to exercise a

claim on resources. The view that means-testing is not consistent with securing social rights partly stems from the historical association of means-testing with local social assistance schemes in which budget constraints exerted a strong influence on methods of administration. Nowadays, a number of states have social assistance schemes which are centrally-financed or placed on a more secure financial footing by other methods. Central financing may bring with it a more rule-based and consistent approach to disability assessment, but this may raise other issues about the way that the disability category is constructed.

Regulatory social policies work by creating rights which stand independently of the processes of provision, and which can be exercised against a range of providers (employers, public agencies etc). Because budget constraints are not explicitly considered in the processes of defining rights in regulatory social policies, such policies may be seen as securing rights more effectively and less conditionally than in budgetary social policies. However, in this chapter we raise some questions about the allocation of resources under regulatory disability policies, drawing on examples from the European states.

#### **4.1 A Typology of Disability Assessment Processes**

In this section we present a simple typology of assessment processes defined along two dimensions:

##### 1. The extent of reliance on medical data

Some systems appear to invest heavily in the acquisition of medical evidence before making a determination on disability. In these systems, the doctors involved in the assessment are usually employed by or contracted to the administering institution, whereas in the less-medically oriented systems, reports from treating doctors (general practitioners, doctors employed by the health service) are more likely to be relied upon. In the systems which rely heavily on medical data, the institution's doctors conduct medical examinations and re-investigate diagnoses, whereas in the relatively non-medical systems the institution's doctor may only review the papers or conduct a functional assessment rather than a full medical examination. In non-medical systems the administering institution does not review the treating doctor's diagnosis of the applicant's condition, and the doctor may be restricted to an advisory role in decision-making, whereas in the more medical systems the decision-maker a doctor is the decision-maker.

##### 2. The discretion vested in doctors and other professionals

As noted in above, it is possible to identify some assessments which seem relatively 'non-medical' in the sense that the amount of medical evidence collected is limited and the discretionary power of doctors is low. Within this category there are two quite distinct groups: those which vest high discretion in other professionals, such as social workers, labour market experts or multidisciplinary teams, and those which aim for a rule-based approach in which professional discretion of all kinds is limited. Among the systems which invest heavily in medical evidence, there are also two sub-groups. There are some 'high evidence - high discretion' systems, and others where medical evidence is interpreted within relatively rigid frameworks such as baremas, which are intended to fetter discretion and enhance consistency.

In this section we outline some of the main features of the four models implied by different combinations of the two dimensions. In s.4.2 we discuss examples from the states included in this study which illustrate some issues about the workings of the different models.

#### A. Low medical evidence and high discretion

In this model, the level of medical evidence collected is low, and the discretion vested in doctors is low, but discretion is vested in other participants. Discretion may or may not be accompanied by localisation. Where a local body has financial responsibility for the provisions it administers, we generally find that high levels of discretion are preserved at the level of the assessment (the 'personal' level). In some cases the local body itself has discretion in the sense that it may develop policies about who should get what, but this discretion is not usually exercised over the disability aspect of assessment (but may relate to means tests or levels of entitlement, for example).

To legitimate the vesting of discretion in non-medical personnel, it is important that they are seen as having relevant professional skills. This model therefore rests on establishing public respect and trust for welfare professionals such as social workers, occupational therapists and employment advisors. Furthermore, the administering institutions are inclined to emphasise that the key issues in assessing claims are not necessarily medical, which helps their staff to maintain their authority over the sphere of knowledge relevant to their work.

#### B. Low medical evidence and low discretion

This model is most often found in settings where central government finances benefits, and then endeavours to control expenditure by setting key parameters for the award of benefits, including rules and procedures to be followed in disability assessment. Central government aims to limit the discretion of doctors and others involved in the process. Model B may be implemented by doctors and may involve the development of specialist disability assessment skills, but these are focused on the relevant social policy area, particularly the assessment of work incapacity.

This model shares some characteristics with model A. The role of medical evidence is limited. Reports may be requested from treating doctors, and the administering institution may employ its own doctors to interpret the reports, but the administering institution does not review the treating doctor's diagnosis of the applicant's condition. Unlike A, the institution's doctors may interview applicants themselves, but only to investigate issues related to functional limitations rather than diagnosis and treatment. Usually, the institution's doctors advise a decision-maker rather than making decisions themselves.

#### C. High medical evidence and high discretion

In the systems conforming to this model, the level of medical evidence collected is high, and the discretion vested in doctors is high. There are important differences in institutional arrangements between the systems exhibiting this pattern and patterns A and B. In particular, health care and benefit administration tend to be more integrated. For example, the health insurer may also provide sickness benefits and/or long-term incapacity benefits. The key

feature of this pattern is that the institution may collect a lot of medical data and may choose to invest considerable resources in specialist investigations for the combined purpose of identifying appropriate health services (including medical rehabilitation) and controlling entry onto long-term income maintenance benefits. By contrast with A and B, a senior doctor may be the decision-maker in these systems.

#### D. High medical evidence and low discretion

The key feature of this model is that the use of medical data is structured by impairment tables or baremas. It is usually doctors who apply these instruments, although there are examples where model D systems have been reformed, sometimes with the social model of disability specifically in mind, to reduce their impairment-orientation. For example, the method of disability assessment prescribed for the administration of LISMI in Spain involves multi-disciplinary teams, and the barema (the VM, described in section 3.2) includes non-medical data. A similar description could be made of the methods used by the COTOREPs in France. However, unlike the instruments used in model B systems, these systems of assessment are not designed for particular social policy purposes, and they use considerably more medical evidence.

## **4.2 Assessment Practices in the European States**

In this section we discuss examples from the states included in this study which illustrate the workings of the four models outlined in s.4.1. While in principle it should be possible to locate every assessment system on the two dimensions, in practice the qualities of some systems are ambiguous. Two problems in particular should be noted. First, 'reliance on medical data' is not the same as involvement of doctors in the assessment process. As noted in the introduction to this chapter, doctors may be asked to make judgments which are not strictly medical. One might expect that doctors will tend to formulate problems in ways which enable them to use their specialist medical knowledge, but this is not inevitable; it may depend, for example, on the doctor's institutional affiliation. We also differentiate between medical examinations which involve diagnosis and description of a person's condition in medical terms, and assessments of a person's ability to perform simple actions (sitting, walking, etc). While doctors often perform the latter type of assessment (sometimes called a 'functional' assessment, although this term is used in different ways across the states), we do not classify these assessments as relying on medical data.

The second problem is in evaluating the degree of discretion exercised by a decision-maker. It is very difficult to tell how much scope for individual judgment a system really allows. It is possible to see whether policy-makers (the government and legislature) have laid down rules and instruments, i.e. whether they have attempted to direct or fetter the exercise of discretion or not. It is much harder to get a sense of whether such rules and instruments really do limit discretion in practice. In particular, impairment tables can be used in ways which allow decision-makers to retain rather a lot of discretion, as is explained in the Council of Europe report on disability assessment (Council of Europe, 2002, pp.14-17).

#### A. Low medical evidence and high discretion

In the wider context of social policy, Model A implies that people with similar needs are

treated similarly, regardless of whether those needs arise from a health limitation or not. Model A is found more in Scandinavia than anywhere else, across the range of income maintenance, employment and ADL assistance provisions. In other states, it is widely found in employment services, particularly those which are oriented towards the 'hard-to-place' (see chapter 3). The strengths of Model A lie in its connection with an integrated approach to social policy. The exercise of discretion is accompanied by strong professional orientations towards identifying and responding to needs. Welfare state professionals may be influential in developing policy responses to social problems. Social policy institutions expect to be politically accountable for their performance and there is a high level of openness and debate around administration.

The negative aspects of model A arise, first, from the potentially negative 'flip side' of giving a powerful role to welfare professionals, and, second, from its reliance on an expansive approach to social policy in which budget constraints do not fetter the discretion of professionals. In employment services, neither of these potentially negative aspects seems to cause much controversy or difficulty. In income maintenance and assistance with ADLs, tighter financial conditions impose some stresses on the high discretion model. Welfare professionals may respond to tighter budget constraints by pressing the government to establish clearer rules of entitlement, so that they are not left taking personal responsibility for making pernicious distinctions. Thus model A may gravitate towards model B when financial pressures are strong. Alternatively, professionals under pressure in the disability field may have recourse to using medical criteria as a rationing device (moving towards model C), as noted in the discussion of LSS/LASS in the Swedish report (see chapter 3).

Issues about the power of welfare professionals have arisen particularly in the area of assistance with ADLs and promotion of independent living. The independent living movement has sought to increase the autonomy of disabled people in making decisions about the organisation of their lives. This movement has been very influential in Scandinavia, suggesting that the relative openness and accountability of Model A social policy institutions enables them to respond to these issues constructively.

In income maintenance, the exercise of discretion within a process-based approach to disability assessment (see chapter 3) seems to reduce the level of conflict over rights. However, the transition to localised administration of the main disability benefits in Denmark has raised some issues. The integration of social assistance, sickness and disability provision at the local level in Denmark, combined with an approach to assessment which emphasises professional judgment over the application of rules and instruments, creates considerable scope for flexibility in the classifications used. The benefit rules (in particular, the alignment of rates for disability benefits with other benefits) suggest that this flexibility is recognised and even encouraged in the interests of effective administration of provisions to promote participation in employment. However, the converse implication is that disabled people are treated in a similar way to other social assistance recipients.

#### B. Low medical evidence and low discretion

Model B is found in the income maintenance area in the UK and the Netherlands, and to some extent in Ireland, although doctors employed by the Irish social security agency appear to have more discretion than in the UK. Model B also characterises the UK's approach to the

provision of assistance with ADLs (Disability Living Allowance). Care insurance in Austria and Germany exhibits some of the same features. Doctors may sometimes do the assessments (in practice, nurses often do them) but they are asked to assess the person's care needs within a fairly tight schedule, not to reinvestigate the medical diagnosis or treatment regime.

While we see Model B systems as essentially non-medical, there are often issues about the exact role of medical evidence in the assessments. One of the issues debated in the Netherlands is whether the limitations identified in the capacity assessment have to be able to be traced back to specified medical conditions. Some physicians argue that medical 'causality' should be identified; others advocate 'finality' whereby the description of the person's limitations is what matters for the assessment. To some extent, this issue also arises in Ireland, where the assessor is directed to assess the limitations in capacity caused by the person's 'certified cause of incapacity' (CCI), which is a diagnosed medical condition, suggesting that limitations which are not related to the CCI may be discounted. In the UK, medical evidence is used primarily to create administrative shortcuts, whereby people with certain medical conditions are deemed to be incapable of work without going through the PCA.

In all three states there is an implicit division of labour between the person's own treating doctor and the doctors employed by the institution awarding benefits, whereby the latter focus on functional limitations and avoid raising issues about the medical diagnosis and treatment regime. However, Model B systems do not always succeed in delineating the roles of the treating doctor and the institution's doctor, and conflicts between them may arise. For example in the UK the British Medical Association has been highly critical of the Personal Capacity Assessment used by the Benefits Agency, and commentators have cast aspersions on the quality of the medical staff employed by the Agency.

From the perspective of the benefit recipient, Model B appears to result in the clear specification of rights. From the perspective of the provider, the model avoids the high demands on administrative resources and problems of consistency and impartiality which arise when needs are assessed in an individualised way. The disability category is constructed to capture information about relevant needs in an efficient fashion. However, the lack of flexibility in the rules and practices adopted means that disabled people and others often have a low opinion of the assessment process and find that it is prone to make arbitrary distinctions. The model strives to be responsive to particular needs related to disability, but the suppression of discretion makes boundary issues very evident. Such criticisms have arisen in all the schemes for assistance with ADLs mentioned above.

A feature of model B is that the assessment of disability is seen as a policy parameter by central government, and reforms to assessment may be undertaken in order to address budgetary or other political concerns. Such reforms have been a prominent feature of disability income maintenance policy in the UK and the Netherlands in recent years.

### C. High medical evidence and high discretion

Model C appears to be typical of social insurance administration in France, Germany, Belgium and Austria. Italian and Spanish income maintenance insurance administration also exhibit Model C features, but without the institutional linkage between health care and benefit administration found in the other states. This is problematic, as it leads to duplication of

medical enquiries in the latter states and tensions between the insurance institutions and health care providers. Since Model C relies heavily on the professional authority of doctors, its legitimacy is damaged by conflicts between doctors. Furthermore, Model C will tend to produce rather high administrative costs because of the use of specialised medical personnel and medical techniques, and this can be seen as wasteful if the process is not linked to the delivery of health care.

The high discretion left to doctors in Model C means that, if the doctor is so inclined, there is scope to take a person's social circumstances into account, alongside the medical condition or health limitation, in making a decision about disability. However, a great deal depends on the governance of the institution that doctors are affiliated to. Where the insurer is held accountable by contributors, for example through the participation of employer and union representatives in its governance structure, we would expect to find that social and economic factors exert some influence on disability assessment. Where the insurer is primarily accountable to central government and mainly concerned about financial control, a highly medical approach may be adopted as a means of restricting claims, as well as reflecting other concerns such as ensuring consistency in decision-making.

#### D. High medical evidence and low discretion

Model D is found in income maintenance insurance in Portugal and Greece and in industrial injury and occupational disease insurance in many states. It is also found in many 'regulatory' settings, i.e. in situations where a general assessment of disability is made which is subsequently used for a range of different social policy purposes. For example, an institution may issue a disability card or pass which entitles the holder to certain provisions. Germany and Austria have disability cards which entitle the holder to provisions such as public transport concessions, parking permits, employment quota places and so on. In Germany the card is awarded by a single authority using an impairment rubric to determine the degree and category of disability; in Austria an impairment rubric is also used but implementation is done by a variety of authorities.

Greece has recently begun to introduce a disability card system. The card is awarded to those who have a rating of 67%+ disabled. The assessment of the 'pathological-anatomical disability degree' is done by health committees formed in health service (hospital) regions, and the committee structure is based on medical specialisms (pathology, surgery, psychiatry). Transport privileges flow directly from the award of a card, but the aim is to use the card to allocate care and other services delivered by the Ministry of Health and Social Care. The award of a card can be seen as a first step towards obtaining these services, but much is likely to rest on the secondary process of allocation whereby services are matched to the person's exact needs and circumstances.

The regulatory model could be seen as creating rights for disabled people which may then be exercised against provider institutions. One consequence of such structures is that providers cannot amend the definition of disability in order to ration their services. However, this may just mean that rationing takes place in other ways (e.g. by queuing or by developing a supplementary set of guidelines). This is problematic for the legitimacy of the external definition and may cast the external process into disrepute as giving rights which are hollow and unactionable. For example, COTOREP in France makes 'orientation' decisions about the

type of employment that a disabled person should take up. However, it cannot ensure that provisions are available to correspond to its orientation decisions. In principle, COTOREP could be seen as creating a legal status of disability along with rights to appropriate provisions, but in practice the agency's independence from providers can be seen as isolation rather than independence, and its effectiveness is questioned, as the national report for France explains in detail.

A feature of regulatory policies is that entitlements follow from impairments without there being any process for ensuring that particular entitlements will be of benefit to the person. Conversely, the value of the rights given by disability status vary considerably from person to person according to whether they can exercise the rights or not (e.g. whether they travel freely, have a car, can get a job, etc). Unlike budgetary social policies, which endeavour to allocate resources according to needs, regulatory social policies are not primarily concerned with the effective allocation of scarce resources. The cost of the regulatory concessions they deliver is spread across providers (employers, transport operators, etc) and is not subject to overall control by a financing authority.

Model D is likely to be prevalent in situations where discretion is seen as problematic (although it is an open question whether impairment tables really constitute an effective method for governing discretion). For example, in private insurance the discretion exercised by insurers in deciding on aspects of disability may be contested by policy-holders on the grounds that the insurer's incentives introduce bias into the exercise of discretion, or more generally that the insurer's governance structure does not regulate the exercise of discretion adequately. To regulate the relationship and reduce transaction costs, the parties may accept the use of impairment tables or other instruments. These instruments differ from those used in Model B systems because they are not designed around specific social policy purposes. Indeed, it may be important that the instruments are seen as having wider legitimacy and as being 'objective' rather than conditioned by particular institutional purposes and requirements.

## **Summary**

The main conclusion of this chapter can be stated simply: there is no ideal method of drawing boundaries between disabled and not-disabled people in social policy. The systems which de-emphasise medical evidence (models A and B) score highly on the criterion of social policy relevance. However, the more medically-oriented systems may enjoy wider legitimacy, particularly if doctors are highly respected and the system avoids situations of open disagreement between doctors.

Model D is the model which is most consistent with establishing a general disability status which might be used across a wide range of policies. It could therefore be seen as having more coherence than the other models. However, it is striking that model D is mainly found in regulatory settings where little attention is paid to the effective targeting of scarce resources. The establishment of a general status of disability does not appear to be consistent with targeting resources to those most in need, which is a primary aim of budgetary social policy.

**PART III**  
**EUROPEAN UNION DISABILITY POLICY**

## DISABILITY AND DISCRIMINATION

In November 2000 the European Union (EU) issued a Directive (Council Directive 2000/78/EC) which established a general framework for equal treatment in employment and occupation and outlawed discrimination based on religion, belief, disability, age and sexual orientation (the ‘framework equal treatment directive’, FETD). Anti-discrimination policy is a relatively new type of regulatory policy. The main aim of this chapter is to examine how this new approach relates to existing policies in the member states. Existing anti-discrimination measures are reviewed, and we also examine how anti-discrimination policy fits with other policies to combat the obstacles that disabled people may face in entering and retaining employment. (Anti-discrimination policy may extend in scope beyond employment, but we focus on employment here as the FETD is confined to employment.)

The FETD does not contain a definition of disability. There are examples in the member states of general prohibitions on discrimination (in national constitutions, for example) where disability is mentioned but not defined. However, the examples discussed here, of more specific and detailed laws against disability discrimination, do contain definitions. They range from broad definitions encompassing minor disabilities to narrower specifications around ‘substantial’ limitations. One aim of this chapter is to elucidate the issues behind the choice of broad or narrow definitions. We do this by showing how different definitions are linked to the different conceptions of equality implicit in anti-discrimination legislation.

### 5.1 Discrimination and Conceptions of Equality

There is considerable ambiguity in the general literature on disability discrimination about whether anti-discrimination law is primarily intended to protect people whose work performance (henceforth: ‘productivity’) is not limited, or only trivially limited, by their condition, or whether people who are substantially limited in what they can do are also seen as potential beneficiaries of the law. This ambiguity reflects different conceptions of equality.

We can start by identifying two broad conceptions: equality of opportunity and equality of results. Equality of opportunity is oriented towards individual merit, in the sense that it aims for equality in the opportunities of individuals to work, and be paid, in accordance with their abilities. This conception is most relevant to disabled people whose productivity is unimpaired and whose opportunities are currently limited by stigma and stereotyping. By contrast, a conception oriented to equality of results, envisaging elements of redistribution and positive action, would appear to offer more to those who have substantial limitations.

These two conceptions seem to be clear alternatives, and clearly imply different definitions of disability. The individual merit approach suggests that the definition should encompass minor impairments, medical conditions which are not substantially limiting in their effect on a person’s activities, and perceived disabilities. It is arguable that no definition at all is needed for the individual merit conception, as the central issue is whether the person has been

discriminated against. The equality of results approach suggests a definition nearer in conception to those found in social policy, which would target a different group of people with substantial limitations.

The ambiguity arises from two sources. First, within the equal opportunities/ individual merit approach can be found a spectrum of tests for discrimination. At one end of the spectrum we find what McCrudden has called ‘equality as mere rationality’ (n.d., p.15), where arbitrary and unreasonable behaviour is deemed discriminatory, but justifications for discrimination are accepted at face value. At the other end of the spectrum we find ‘equality as fairness’, where justifications are examined critically, the possibility of indirect discrimination is recognised, and burdens of proof may be shifted. Many commentators argue that reasonable accommodation for disabled people comes within an ‘equality as fairness’ conception of the scope of anti-discrimination law. Others see accommodation as a form of positive action. For the purposes of our discussion, focusing on definitions, the central question is whether a right to accommodation is consistent with a broad definition of disability (or no definition) or whether the right has to be confined to a narrowly-defined group of people.

The other source of ambiguity arises from the development of a third conception of equality which goes beyond the individual merit approach but avoids the explicitly redistributive language of equality of results. This conception could be described as ‘radical equality of opportunity’ as it argues for institutional and structural changes to remove the barriers to equal participation for disabled people. It involves the creation of positive duties on employers to promote equality, for example by reviewing employment practices, workplace organisation, etc. It is not clear what definition of disability should accompany this conception. In this chapter we show that, among the anti-discrimination policies of European states, there are some examples of policies which conform to this conception. However, they are group-oriented policies which do not rest on the establishment of individual rights of litigation and therefore do not require the definition of particular individuals as disabled.

To illustrate how these different conceptions of equality are reflected in states’ policies, we have selected just five states to study in detail. These include the three states which have recently passed disability anti-discrimination legislation: Ireland, the UK and Sweden. Norway is included as providing an example of a ‘radical equality of opportunity’ approach which is partly group-oriented. Finally we discuss the example of France, which has a more traditional (and longer-established) combination of measures reflecting, on one hand, a narrow, equality-as-rationality approach to individual merit and, on the other hand, redistributive policies oriented towards equality of results. In the discussion of each state’s provisions we ask three main questions:

1. What definition of disability do they use?
2. What conception of equality do they incorporate? and
3. What is the role of individual litigation and what, if any, group-oriented measures are envisaged?

#### *(a) Ireland*

In Ireland the Employment Equality Act (1998) prohibits discrimination in employment and in other spheres of life on a number of grounds, including disability. A definition of disability is provided in section 2 of the Act, which states that disability means:

- a) the total or partial absence of a person's bodily or mental functions, including the absence of a part of a person's body;
  - b) the presence in the body of organisms causing, or likely to cause, chronic disease or illness;
  - c) the malfunction, malformation or disfigurement of a part of a person's body;
  - d) a condition or malfunction which results in a person learning differently from a person without the condition or malfunction, or
  - e) a condition, illness or disease which affects a person's thought processes, perception of reality, emotions or judgement which results in disturbed behaviour;
- and shall be taken to include a disability which presently exists, or which previously existed but no longer exists, or which may exist in the future or which is imputed to a person.

Thus the Irish definition encompasses minor and perceived impairments, and does not require that a person's limitations be substantial.

The conception of equality in the current law is indicated by the history of the Act. The original Employment Equality Bill (1996) was declared unconstitutional by the Supreme Court (Judgment 118/97, 15 May 1997). It found that the requirement to accommodate disabled workers unless this caused the employer 'undue hardship' did not strike an appropriate balance between the employer's constitutional right to property and the principles of social justice which could regulate that right. The Court accepted that it was in accordance with social justice that society should ensure the provision of accommodation for disabled people. However, it argued that to place the cost of accommodation on individual employers was not appropriate: the cost of the social obligation to accommodate should be distributed across society. The Court drew attention to the vagueness and uncertainty of the obligations on employers: 'the financial circumstances of the employer' could be taken into account in determining the duty to accommodate, but this was not within the framework of a proper system for the disclosure of financial circumstances (such as a tax system). The Court also noted the wide definition of disability in the Irish Act, which covers even minor impairments and future disabilities, which, it argued, introduced an unacceptable level of uncertainty into the costs which might be faced by an employer.

The Act as passed in 1998 incorporated amendments reflecting the Supreme Court's decision, and requires employers to accommodate only if the cost is 'nominal'. This suggests that, as it stands, the conception of equality in the EEA is based on individual merit, and veers towards the 'equality as rationality' end of the spectrum, addressing discrimination based on prejudice or stereotypes but not requiring an employer to take significant steps to accommodate a disabled person. However, it is possible that the authorities will implement an 'equality as fairness' conception despite the constraints of the nominal cost restriction. In a recent case (EED026, 04/07/02), the Labour Court upheld a discrimination complaint by a worker with a hearing impairment. It held that the employer could reasonably have been expected to buy an appropriate telephone headset for the worker as the cost of 450 euros was 'nominal' in relation to the company's turnover. It also held that reasonable accommodation extended to training, and that the company had failed to provide basic induction training.

Furthermore, the Act creates some positive duties to promote equality, despite the limits to positive action in favour of individuals. The Act established an Equality Authority with

powers to develop codes of practice which have enhanced legal standing (s.56). The Equality Authority has powers to promote equality through Equality Reviews and Action Plans (ss.69-70). However, these powers do not create individual rights of litigation for disabled people.

*(b) The United Kingdom*

The UK Disability Discrimination Act 1995 (DDA) defines disability as ‘a physical or mental impairment which has a substantial and long-term adverse effect on a person’s ability to carry out normal day-to-day activities’. Schedule 1 of the Act amplifies on this definition, and the Department for Education and Employment has provided further guidance. There has been considerable debate about the definition and there is some case law on the subject, although the definition has not assumed the central place in DDA litigation that it has acquired under the Americans with Disabilities Act (ADA). This possibly reflects differences in the institutional context. The processes involved in bringing a DDA case are considerably less complex and legalistic than in the US (Baker, 2002).

The requirement that a person be ‘substantially’ adversely affected points towards a ‘protected group’ philosophy and could be consistent with an element of redistribution and positive action in favour of disabled people. Indeed issues have arisen as to whether the Act protects less-disabled people who are treated unfairly as a result of their disability but who are not substantially limited in what they can do. Disfigurement is specifically mentioned as attracting protection (its effects are deemed ‘substantial’ even when the person is capable of carrying out all normal activities (s.3.1)). However conditions such as cancer and HIV-positivity have proved problematic. People dismissed (or adversely treated in some other way) when their cancer is at an early stage or in remission have faced problems bringing DDA cases, because they cannot always establish that their condition is likely to progress to having substantial and long-lasting effects on normal activities. The government has broadly accepted that these situations should be covered by the Act and is currently conducting consultations on how to implement changes.

The Act envisages that those included in the protected group have special rights to accommodation. The cost of accommodation must be reasonable, but need not be merely nominal. Tribunal cases suggest that employers should expect to have to demonstrate that they have investigated the possibilities for accommodation before dismissing a worker. The case law also establishes that reasonable accommodation may involve physical adjustments to the workplace, but may also involve changes to a person’s job description, redeployment, or changes to the work time pattern (e.g. time off for medical treatment). Some public financial assistance is available for adaptations (through the Access to Work scheme).

While the restrictive definition of disability and the reasonable accommodation clause might suggest that the DDA is founded on an ‘equality of results’ conception, it is arguable that many cases are actually based on individual merit. DDA cases are heard by specialist Employment Tribunals, which are experienced in unfair dismissal cases and other aspects of employee rights. The Tribunals are accustomed to looking critically at employers’ actions and balancing the employer’s right to manage against the interests of workers. This inclines them towards an ‘equality as fairness’ approach to discrimination, whereas ordinary courts may be more inclined to restrict themselves to the firmer judicial territory of ‘equality as rationality’. It is

also significant that there are many DDA cases where the issue of the definition of disability does not arise. Very often the employee has a case under the law relating to unfair dismissal alongside the DDA claim, and is thereby able to utilise the general rights of employees in founding the claim.

The implementation of the UK Act has been strongly oriented towards the exercise of individual rights through litigation. A study of the first nineteen months of the Act's operation found that 2,456 cases had been registered during this period. Of the cases that had reached an outcome, some 40% were settled through conciliation and arbitration, while 20% had gone to an employment tribunal hearing (Meager et al, 1999).

The original DDA provided for relatively weak group-oriented policies, as the National Disability Council had limited powers. In April 2000 a Disability Rights Commission was established in place of the Council, with an extended remit of supporting individual actions which had wider policy ramifications and developing codes of practice and other measures to promote equality.

*(c) Sweden*

Sweden passed an Act Prohibiting Discrimination in Working Life against Persons with Disabilities in 1999 (SFS 1999: 132). Disability is understood as 'enduring physical, mental or learning limitations of a person's functional capacities that have occurred at birth or later or can be expected to occur as a consequence of injury or disease'. A person's limitations do not have to be substantial.

By contrast with the UK, the Swedish law does not attempt to circumscribe the definition of the 'protected group', but, by contrast with Ireland, the employer can be required to provide support and adaptation measures which cost more than a nominal amount. Instead, the cost must be such that the employer can 'reasonably be required' to implement the measures (s.6). One explanation of the difference between the Swedish approach and that taken in Ireland is that Sweden has in place ordinances on the provision of working aids and other special measures which provide public financial support to employers to facilitate accommodation. It is also arguable that there is less concern about the scale of burdens on employers in Sweden because there is already an extensive set of employee rights relating to such things as health and safety at work and the regulation of working time. Health and safety obligations under the Work Environment Act mean that employers are required to ensure that workplaces do not injure or cause long-term harm to their workers. Some workplace adaptations in response to a disabled person's specific needs might be brought under this rubric (James, 2000). It would follow that the cost of accommodation for a disabled person might be judged 'reasonable' if it is comparable with the cost of measures which employers might be expected to adopt for any employee, such as the provision of improved lighting or ergonomic adaptations.

In terms of the conceptions of equality outlined above, the Swedish approach seems to go beyond the individual merit conception to incorporate elements of positive action towards achieving equality of results. However, whereas equality of results is often thought to require the limitation of rights to members of a selected group, the Swedish approach suggests that positive action may be 'mainstreamed', in the sense that all workers have certain rights to

positive action. The opportunity for personal development through employment is a central idea in the Swedish welfare model. Individual rights regarding access to training and protection against dismissal are well-developed, as are rights for workers as a group in the form of codetermination provisions. The Swedish approach appears to be oriented, at least in part, to advancing the interests of disabled people through general measures applying to all workers in employment.

Central to the implementation of the 1999 Act is the office of the Disability Ombudsman (Handikappombudsmannen, HO). HO receives and investigates complaints from individuals as well as giving advice and undertaking investigations into the situation in particular sectors (e.g. accessibility of public buildings). In the area of working life, prima facie cases are referred to the complainant's trade union which may negotiate a settlement with the employer. If the trade union declines to act, HO itself may undertake negotiations. In the sample of cases described on HO's website ([www.handikappombudsmannen.se](http://www.handikappombudsmannen.se)) there are several cases where the trade union has declined to take action and HO has subsequently obtained a substantial settlement for the disabled person. This suggests that institutions which have been established to advance workers' interests collectively are not always oriented towards acting to promote the particular interests of disabled people.

Where a negotiated settlement cannot be achieved, the case may be heard by the Labour Court. At time of writing, there had been no court cases, suggesting that the Swedish approach will be to rely more on conciliation and negotiation than litigation.

*(d) Norway*

In Norway, there is no specific anti-discrimination act relating to disability, but the Work Environment Act (WEA) contains a number of relevant provisions. As with the Swedish WEA, the Norwegian Act creates duties on employers to provide employees with scope for personal and vocational development and self-determination, as well as creating a safe environment at work. The guidance to the Act suggests that the general regulations regarding the design of the working environment are of particular benefit to disabled people.

The WEA includes some provisions specifically concerned with disabled people. Section 13(1) requires that the employer set up the workplace in a way which permits access to disabled people, as far as this is possible and reasonable. This duty applies whether or not the enterprise currently has disabled employees, so it is not oriented towards the needs of a particular disabled individual. S.13(1) would seem to be an example of a 'radical equality of opportunity' conception which places a general duty on employers to promote equality, at least so far as the physical organisation of the workplace is concerned. However, the guidance states that the labour inspectorate will not normally require adaptations to workplaces 'before the need arises'.

Section 13(2) of the WEA sets out the obligations of the employer towards an employee who becomes disabled. The definition of disability is a broad one. The guidance to the Act emphasises that 'employees have individual abilities and highly different capacity for work. Many have particular problems in relation to work. These may be related to various factors such as somatic or mental illness, injury, defect, the effects of drudgery or aging, etc.' The

guidance does not attempt to distinguish between problems which have their origin in recognised medical conditions and those which are the result of social and complex factors. The philosophy behind section 13(2) seems very similar to the Swedish approach based on general rights accorded to all workers. The conception of equality appears to envisage some redistribution, with ‘mainstreamed’ positive action for a wide range of disadvantaged workers. However, rights under s.13(2) are confined to already-employed workers. Financial support for adaptations which may be required by a particular worker may be provided under the National Insurance Act. This financial support relates to the individual’s needs and is not available to finance the general duties specified under s.13(1).

A third provision relevant to disability in the WEA is section 55A. This recent amendment makes it illegal for employers to discriminate on grounds of disability when engaging workers. Direct and indirect discrimination is prohibited, and reasonable accommodation is provided for. However, there is as yet no regulation or guidance on the definition of disability under s.55A, and no cases have been brought to court.

*(e) France*

France passed a general law prohibiting discrimination on the grounds of health or disability in 1990 (No.90-602 of July 1990). Its origins lay in an outcry over discrimination against people who are HIV-positive, but its scope is wider. The law made a succession of amendments to the Penal and Labour Codes, adding the words ‘health or disability’ to existing prohibitions on discrimination on grounds of race, nationality, religion, morals or marital status. Disability is not defined in the law, but the use of the expression ‘health or disability’, and the history relating to HIV, suggests that any medical condition or impairment may be covered, whether or not it has a substantial effect on a person’s activities. The scope of the 1990 law was recently extended by Law No 2001-1066 of November 16, 2001 relating to the fight against discrimination. This law amended Art L.122-45 of the Labour Code to include a wider range of discriminatory grounds, as well as making a number of other amendments regarding scope and remedies. Disability and health are now covered, along with physical appearance.

There is no mention of reasonable accommodation in the 1990 law. However, accommodation is envisaged by other measures in the Labour Code, notably Art L.122-24-4, which applies if an existing employee is declared by the occupational doctor to be incapable of resuming his or her previous work. The employer must investigate suitable alternative employment and make necessary adjustments to the workplace. L.122-32-5 notes that financial assistance from the state (specifically, from AGEFIPH) may be available for these adjustments.

As is outlined in Appendix 2, the work of AGEFIPH revolves around the administration of provisions to promote the employment of people who are recognised as ‘handicapped workers’ (*travailleur handicapé*, TH). Decisions about the classification of a worker as TH are made by the COTOREPs. Under Art L.323-10 of the Labour Code, a handicapped worker is ‘any person whose possibilities for obtaining or maintaining employment are effectively reduced as a result of insufficiency or reduction in physical or mental capacities’. There are three categories of severity. Category A designates a ‘light handicap allowing satisfactory adaptation to [mainstream] work’; categories B and C designate more severe handicaps.

The laws of 1990 and 2001 contain important limitations regarding ‘medical inaptitude’ for work. Under Article 3 of the 1990 law, the general prohibition on discrimination does not apply when an employer’s refusal to recruit, or decision to dismiss, is founded on the worker’s ‘inaptitude’. Article 9 includes the prohibition on the grounds of health or disability into the Labour Code, but excludes inaptitude certified by a doctor qualified in occupational health (*médecin du travail*). Article 10 applies the prohibition on discrimination to the civil service, but makes a similar exception for taking account of a person’s physical inability to perform certain functions. Thus it appears that the law primarily protects people with adverse health conditions whose fitness for work is unimpaired (in direct contrast to the failure to protect this group in the UK). Coupled with the absence of a general right to reasonable accommodation, this suggests that the conception of equality implicit in the law is based on individual merit and veers towards a narrow basis in ‘equality as rationality’. A great deal depends on the view taken by the occupational doctor on how a medical condition affects a person’s aptitude, but the structure of the law is that any inaptitude takes the person out of the domain of anti-discrimination legislation and into the realm of the ‘handicapped worker’.

Thus there are two quite separate sets of measures in France which apply to two distinct groups of people. The workers who can claim protection under the 1990 and 2001 laws are not classified as ‘handicapped workers’, and do not attract subsidies or count towards compliance with the TH quota. They cannot claim accommodation, but they don’t need accommodation because their fitness for work is unimpaired. Workers who do need accommodation are classified as ‘handicapped workers’. They are, potentially, the beneficiaries of various social policy measures. A worker who becomes handicapped while in employment has certain individual rights against the employer, but generally anti-discrimination law does not apply to handicapped workers.

## **5.2 The Scope of Rights and Rationales for Restrictive Definitions**

In this section we discuss the issues behind the choice between restrictive and expansive definitions of disability in the area of discrimination. The UK provides the sole European example of a restrictive approach to definition in anti-discrimination law. As we have seen in previous chapters, all states maintain definitions that are more or less restrictive in social policy.

The main idea motivating the use of a restrictive definition in the UK was that the potential cost for employers of complying with the DDA had to be controlled by limiting the size of the protected group. (Secondary ideas included the desire to prevent excessive litigation by people with minor impairments.) In Sweden, to take a contrasting example, there was not so much concern about cost control. We have suggested that this was partly because of the existence of social insurance for some measures, and partly because of the high standard of rights to a satisfactory work environment enjoyed by employees in general.

The use of a restrictive definition to control costs presents a paradox. A commonsense view might be that a person with a minor disability should be able to invoke anti-discrimination legislation if he or she is unfairly treated because any necessary accommodation should be of nominal cost (because the disability is minor). It therefore seems counterintuitive to exclude

this group on the grounds of potential cost.

However, the issue is not quite as simple as this. A problem case arises when a person requires expensive accommodation to work in a particular job (A) but not in other jobs (B-Z). It is arguable that one purpose of a restrictive definition is to prevent the person being able to claim accommodation in job A. Under the UK definition, for example, the person might be found not to be substantially limited in his or her activities, which would prevent a claim in job A. The person would be expected to take up jobs in areas B-Z and to accept that A was closed off.

This scenario may seem a little far-fetched, but the issue of whether a person should be able to benefit from a designation of disability in one job when he or she could work with less accommodation in another job is a real one. The problem is that it is cumbersome to endeavour to answer this question through the definition of disability. Social policy institutions such as public employment offices routinely adopt views about people's appropriate job choices. (In some states, these are codified into formal rules on occupational preferences, wage conditions, travel time etc., particularly in unemployment benefit administration.) Officials often consider a range of factors, such as the person's age, education and work history. An employment officer seeking to help a disabled person into work may consider such factors along with considerations arising from the person's medical condition and limitations, and may take a view about whether the costs of accommodation in a particular job are reasonable and comparable with the costs which would arise in other possible jobs.

One of the ways in which the legislation reviewed in s.5.1 addresses the issue of job choice is by establishing stronger rights for existing employees than for prospective employees. Existing employees are, implicitly or explicitly, given the right to accommodation in their existing job or with the same employer. The question of whether the person is sufficiently disabled in general life activities that accommodation would be needed in any job is not necessarily considered. This is explicit in, for example, the Swedish 'step-by-step' process, which comes into play when a person is unable to continue work due to long-term illness or injury (see Appendix 1). The first step is to see whether the person can resume his or her previous job with adaptations and adjustments. Possible job changes and re-training with the same employer are considered next. If these steps do not lead to a resumption of employment, other job options are considered.

The establishment of rights to reasonable accommodation for existing employees can be understood as arising from the established corpus of laws and practices governing employers' obligations to their employees. The European social model is one of extensive employee rights, by contrast with the US situation. Most European states accord employees an extensive set of rights against the employer after a minimum period of employment. These rights include the right to sick pay and paid parental leave, various protections in circumstances of individual and mass redundancy, and protection against unfair dismissal. In some states, limited rights to request part-time work (and have the request reasonably considered) have been introduced. These rights can be exercised by any employee who is in a relevant situation (e.g. who becomes ill, has a child, etc).

The French provisions on reasonable accommodation come within the framework of employee rights, and are limited to that context. Even when the law is framed to apply to both existing

and prospective employees, as in the UK, it is liable to be most effective for existing employees. The UK is usually seen as having relatively weak employee rights, but, as discussed in s.5.1, existing protections against unfair dismissal have, arguably, facilitated the effective operation of the Disability Discrimination Act.

However, building disability rights on the existing corpus of employee rights has the important limitation that the rights created are confined to those in employment. While many people who face late-onset disabilities may be protected by such measures, those seeking access to employment do not benefit. From this perspective, one purpose of a definition of disability is to establish a standard for specifying who has rights under anti-discrimination legislation which is common to both existing and prospective employees, and avoids setting different standards for ‘insiders’ and ‘outsiders’. This is a laudable ideal, but it comes up against a very basic problem about the fair allocation of costs across employers. The difficulty for a job-seeker is that no employer has any particular or special duty towards him or her, relative to other employers. An employer (A) faced with a prospective employee who requires accommodation may ask why the cost should fall on A, and not on other employers B-Z. We suggest that narrowing the definition of disability does not provide an effective way of resolving the problem of allocating burdens across employers. Where the costs of accommodation are significant, some public or social financing structure clearly provides the most direct and effective method of spreading burdens.

### **5.3 Anti-Discrimination Definitions and Social Policy Definitions**

The review of member states’ legislation in s.5.1 showed that several states provide financial support to employers to pay for accommodations for disabled employees. This financial involvement may serve to facilitate acceptance of anti-discrimination legislation by employers. The Irish Supreme Court decision suggests that some sort of public financing structure to distribute the costs of accommodation could be seen as necessary to protect employers’ right to property. Conversely, the existence of anti-discrimination obligations may encourage employers to take up publicly-funded accommodation measures, which otherwise may suffer from low take-up.

However, the relationship between anti-discrimination legislation and social policy is not necessarily entirely symbiotic. Difficulties may arise because different institutions, with different values and assumptions, are involved in administering the two spheres of intervention. For example, a court could accept a disabled person’s claim to be accommodated, subject to financial support being available to the employer, and then the social policy agency could decide that the person did not qualify for assistance according to its rules.

In the UK, employment programmes come within the ambit of the DDA, and a decision by the Employment Service not to assist a person who came within the scope of the DDA could, in principle, be challenged. In Ireland, positive measures in favour of disabled people are permitted under s.33 of the Employment Equality Act, where the measures are ‘intended to reduce or eliminate the effects of discrimination’. Various provisions prevent challenges to measures targeted to disadvantaged groups; for example, the provision of special treatment or facilities for a disabled person does not create a right to the same facilities for a person without

a disability, or a person with a different disability (s.35). Nonetheless, the idea that social policies should be consistent with anti-discrimination principles has contributed to some changes to Irish employment programmes; in particular, to reforms to the structure of training allowances.

Other possible conflicts between anti-discrimination principles and social policies can also be imagined. Quota systems could be challenged for using definitions of disability which are themselves discriminatory (quota definitions often exclude, or give low ratings to, mental illnesses, for example). Employers might contest claims from disabled people who do not qualify for social policy measures on the grounds that the measures define the extent of employers' obligations and distribute their cost, and that additional responsibilities should not be introduced by the 'back door' of discrimination law.

However, it is arguable that transposition of the FETD should not result in conflicts between anti-discrimination law and social policy. There are several reasons for this. First, the Directive explicitly excludes from its scope social security, social protection, and 'any kind of payment by the State aimed at providing access to employment or maintaining employment'. Thus its scope is narrower than the UK and Irish legislation. Second, Article 7 explicitly permits positive action, although this action should be 'with a view to ensuring full equality in practice' by preventing or compensating for disadvantages on the specified grounds (e.g. disability). Third, commentaries on the FETD suggest that it is intended to implement an 'individual merit' approach to equality, albeit one which lies at the 'equality as fairness' end of the spectrum described at the start of this chapter. The FETD does not require member states to introduce measures to achieve equality of results.

We began this chapter by suggesting that an 'individual merit' approach is consistent with a broad definition of disability, but we noted that some commentators take the view that the right to accommodation has to be confined to a narrowly-defined group of people. Our review of established practices in member states suggests that this argument is not a strong one, for two reasons. First, some rights to accommodation may be encompassed within the general regime of employee rights. Second, limiting the right to accommodation does not resolve the problem of ensuring an equitable distribution of the costs of accommodation across employers, which is much more effectively addressed by public funding for costly accommodations.

However, these arguments also imply that it is difficult to establish principles about what level of accommodation is reasonable which can be applied generally across the member states. The general regime of employee rights differs across member states, as does the availability of public funding for costly accommodations. It is arguable that the FETD allows that norms as to reasonable accommodation may vary across member states in the light of each state's social policy. This is one interpretation of the last sentence in Art 5 on reasonable accommodation, which states that the burden on employers of taking appropriate measures to accommodate people with disabilities 'shall not be disproportionate when it is sufficiently remedied by measures existing within the framework of the disability policy of the Member State concerned'.

In the introduction to this chapter, we noted the development of a third conception of equality which we described as 'radical equality of opportunity'. The review of states' policies

indicated that there were examples of the creation of positive duties on employers to promote equality. However, these duties are enforced through the activities of authorities and commissions charged with promoting equality, rather than through the creation of individual rights of litigation. In several states, duties to promote equality co-exist with individual rights to litigate, although there are considerable differences of emphasis, with the UK being highly oriented towards individual litigation and other states much less so. In Denmark, considerable opposition to the model of individual litigation has been expressed. The Danish Disability Council and its affiliate, the Equal Opportunities Centre for Disabled Persons, are charged with implementing equal treatment through the principle of 'sector responsibility', whereby responsibility is placed on every sector in society to ensure equality of access to disabled people. The Equal Opportunities Centre was established by a parliamentary decision in 1993 which noted the anti-discrimination legislation adopted in the US and suggested that special legislation of that kind was contrary to Danish traditions. Some of the same concerns are reflected in the Swedish preference for resolving disputes through negotiations between trade unions and employers, although it is evident that an effective route for resolving individual grievances is also open in Sweden.

The FETD does not contain explicit provisions creating positive duties to promote equality, but it does urge member states to step in this direction through the promotion of social dialogue and dialogue with non-governmental organisations (Arts 13 and 14). Placing the FETD in its wider context, it can be seen as a measure which does not rely entirely on individual litigation for its effectiveness. The value of the FETD might come from its contribution to the framing and visibility of particular issues in social policy as well as from the strict requirements of transposition. Frequently, disability rights campaigners are highly critical of the institutions which implement social policies such as quotas and rehabilitation services. Anti-discrimination law could provide an alternative set of principles through which the principles and assumptions governing policies towards disabled people can be opened up for fresh scrutiny. From this perspective, the concepts of discrimination and equal treatment raise issues about the principles and assumptions governing social policies towards disabled people, although member states' social policies lie outside the scope of the Directive.

## FREEDOM OF MOVEMENT FOR PEOPLE WITH DISABILITIES

As explained in chapter 1, the Commission in its tender document signalled that its interest in definitions of disability arose from several different concerns. One specific problem it noted was the lack of mutual recognition of national decisions on disability and the impact of this on disabled people moving within the Union. The Commission made it clear that it was not seeking recommendations that member states should change their definitions in particular ways to enhance the mobility of disabled people. Instead, it sought ways in which different definitions could be understood and compared, for example by establishing general concepts and descriptions. This research has sought to do this by setting out a common language to describe the different approaches taken and by establishing frameworks within which national policies can be described (chapters 3 and 4 and Appendices). This chapter discusses the implications of the findings of this project for issues relating to rights of residence (s.6.1), exportability of benefits (s.6.2) and mutual recognition of decisions on entitlement to benefits (s.6.3).

Free movement in Europe is governed by two main sets of provisions: provisions on the right to take up residence in another state and be treated without discrimination on grounds of nationality, and provisions on the exportability of certain social security benefits. We can derive two concepts of free movement from these two sets of provisions. One concept is based on non-discrimination, whereby a European citizen is treated as a host state national wherever he or she is resident. On this concept, there would be free movement for European citizens if they could take up residence wherever they chose and claim benefits as if they had always lived where they now resided, with periods of residence in other states treated as residence in the host state, events which occurred in other states treated as having occurred in the host state, etc. The legislation of member states guarantees different and unequal social security advantages, and under the non-discrimination concept people would find that, when they moved between the states, they would encounter different levels of social provision, along with different organisational structures, mixes of cash and benefits in kind, and so on. In the absence of any reason to the contrary, we can see these differences between states as being part of the fabric of social and economic differences between the states, which mean that the mover can expect to be better off in some ways and worse off in others.

The other concept of free movement, from which exportability is derived, is based on security of property rather than non-discrimination. Central to this concept is the protection of rights derived from having contributed to social security. Contributions are seen as giving the mover a property right which can be made private, in the sense of being attached to the person and moving with him or her, rather than having to be exercised in a particular social setting. If a person takes out an insurance contract with a private company, there is no inherent reason why the scope of the contract should be bounded territorially, and with the development of Europe as a unified economic space, we find that territorial boundaries in private insurance coverage are increasingly being eliminated. In social insurance, workers take out insurance according to where they work, i.e. on a territorial principle (sometimes in conjunction with occupational and other criteria governing the coverage of different arms of social insurance). If exportability is applied, claims against the insurer are not territorially bounded.

## 6.1 Rights of Residence

The current position in European law is that the right of residence is broadly operational for workers, who have the right to take up residence in any state where they obtain work, and must be treated without discrimination in the allocation of social benefits and advantages in the host state (the relevant details are in Regulation 1612/68, although the principles involved could also be derived directly from the Treaty). Disabled people who are unable to work are excluded from the personal coverage of these provisions, although they may utilise the provisions on family unification.

For non-workers, the right to take up residence in another member state is highly constrained. Under Directive 90/364, a state may refuse residence to a non-working migrant who does not have sufficient resources to ensure that he or she will not be a burden on the host state's social assistance system. It is sometimes argued that exportability of benefits can provide the basis for free movement by ensuring that movers have sufficient resources, but this argument does not really stand up to scrutiny. Only if exportable home state benefits are adequate to support the person in the host state will this argument work: broadly speaking this means that people will be able to move from high-income states to poorer states, but not from poorer states (where benefits are lower) to richer states (where the cost of living is higher).

The Commission's proposal for a Directive on the right of citizens of the Union and their family members to move and reside freely within the territory of the Member States (COM(2001) 257 final, 23.5.01) would address some of the current limitations on freedom of movement for disabled people. Particularly significant are:

1. The widening of the concept of the 'family' for the purposes of family unification and the removal of rules about dependency. These provisions would benefit people with disabilities by acknowledging the possible importance of relationships of care and support between adults other than spouses, by allowing unification for relatives in the ascending line and for adult children, and also by recognising that dependency is a continuum: a person may have some financial resources while at the same time needing care and support from another.

An example of the possible impact of this proposal is provided by the facts in *Snares* case. Under the proposal, Snares, a disabled man, would have the right to join his mother in Spain regardless of whether he had sufficient resources. In the case, it was argued that Snares should be able to export Disability Living Allowance in order to protect his right of free movement, although this argument was rejected by the Court.

2. The establishment of a right of permanent residence after four years' residence in another state. This provision is potentially important in protecting European citizens who become disabled while living in a state other than their state of nationality.

It is interesting to note that the proposal for a Directive contains no specific mention of disability, yet it would have potentially very favourable effects on the freedom of movement of disabled people in Europe. The proposal falls into the group of measures discussed in Chapter 1 which are general rights, potentially exercisable by any citizen, but likely to be of particular

value to those with a disability. The proposal is very much in conformity with the social model, as it reduces or removes existing barriers to free movement which have particularly adverse effects on disabled people.

The proposals on the right of residence entail some extensions to the application of Reg 1612/68, basically to ensure that there is no discrimination between resident nationals and other permanent residents. For disabled migrants, these provisions imply that they will be subject to the rules of the host state governing non-exportable disability benefits. Because the host state must apply its rules in a non-discriminatory fashion (as between nationals and non-nationals), it is not necessary to establish a common definition of disability across states or to take steps towards mutual recognition of decisions about disability in order to protect freedom of movement.

## **6.2 Exportability of Benefits**

The second concept of free movement outlined in the introduction to this chapter is concerned with the defence of the property rights of movers, i.e. whether people have security of property in their social benefits when they move. The most obvious reason to grant people private property rights in social security benefits is that the benefits represent the counterpart of contributions which they have paid. This is the underlying principle in many decisions on exportability. For example, in the *Molenaar* case, the Molenaars paid contributions in their country of employment (Germany) and taxes in their country of residence (France). Their case was simply that, if they were required to purchase care insurance, they should be entitled to receive care insurance benefits. The Molenaars appear to have been content with the possibility that they should not contribute to German care insurance, which would mean that they would rely on the services provided by the authorities in France if they were to need care eventually. However, the Court found that it had no authority to exempt them from care insurance contributions, and it held instead that they should be entitled to care insurance benefits.

While it seems evident that the concept of contribution is necessary to the establishment of a property right in a benefit and is therefore necessary to exportability, the principle of contribution is not explicitly stated in Regulation 1408/71. One explanation is that some member states could evade the spirit of the regulation by financing 'insurance-like' benefits from general taxation. This would be unfair to migrant workers, who would pay taxes as residents while working but could then find themselves with no exportable benefits. Regulation 1408/71 avoids this problem by using indirect indicators of the rights a person might be expected to acquire while working. There are two main indicators:

- the risks covered, which are listed in Article 4(1). They include old age, invalidity, sickness and unemployment.
- the nature of the entitlement, i.e. 'without any individual and discretionary assessment of personal needs, to recipients on the basis of a legally-defined position'.

The first indicator reflects the pattern of provision in the member states, whereby people often acquire coverage against the risks specified by working. The second indicator endeavours to draw the borderline between social security and social assistance in terms of the clarity and security of the rights created.

We can see that the formulation adopted in Reg 1408/71 presents a difficulty with benefits which have a 'dual' nature. Dual-nature benefits are those which may be derived from having been a worker, but which also contain provisions for supplementing, or even replacing, work-based entitlements. These supplements and substitutes are normally designed to achieve a minimum standard of provision for people with interrupted work histories or limited earnings records. The range and scope of these supplementary benefits has increased in the member states in the last 20-30 years, as states have sought to respond to new needs, higher unemployment, issues about the social security rights of women, and other social and economic changes. States have substituted new benefits in areas previously covered by social assistance, and/or improved their social assistance schemes so that entitlements are more clearly defined, administration is less intrusive and, in some cases, national financing can take over from local financing. From the perspective of reducing poverty and inequality, these developments are highly desirable, but they present a conceptual problem for the application of Reg 1408/71. On one hand, they give clearly defined rights; on the other hand these rights flow from social solidarity rather than from contribution, and therefore do not assimilate well to the privatisation of property rights entailed in exportability.

Regulation 1247/92 can be seen as a response to these issues. It allowed member states to prevent the export of certain benefits which were (a) non-contributory and (b) provided supplementary, substitute or ancillary cover for the risks specified in Article 4(1) of Reg 1408/71, or provided specific protection for the disabled. Reg 1247/92 also contained measures to enhance the ability of residents to claim benefits. Requirements for a certain duration of residence and restrictions on paying benefits for risks which first arose in other states are prohibited for benefits designated as non-exportable under Reg 1247/92.

The relationship between the two classes of risk - those covered by Art 4(1) of Reg 1408/71 and those mentioned in Reg 1247/92 - raises some interesting issues in the area of disability. Invalidity benefits are listed in Art 4(1), while Reg 1247/92 uses the different term 'disabled'. In the light of the above discussion, it would seem that the implicit distinction is between risks which are related to work, and risks which arise independently of work. The term invalidity refers, in this context, to incapacity for work. While it is possible to be unable to work without ever having worked (e.g. if disabled from birth or a young age), invalidity benefits usually require some work history in order to be entitled. Benefits for those who have never worked, or have not worked enough to qualify for the main contributory benefits, would appear to come under the rubric of supplementary, substitute or ancillary cover, or specific protection for the disabled.

The application of the terminology to provisions for assistance with ADLs - care insurance and other similar measures - has proved to be problematic. Provisions for assistance with ADLs may be classified with invalidity benefits if they require a person to be unable to work. In some states, provisions for assistance with ADLs are only payable to people in receipt of full invalidity pensions, in which case inability to work is effectively a criterion and the provisions can be seen as supplements to invalidity benefits. Such provisions will generally be exportable. However, not being able to work or not working due to retirement is not a criterion for many of the provisions for assistance with ADLs we examined, including German care insurance. In *Molenaar*, the Court decided that German care insurance benefits should be regarded as sickness benefits, bringing them under the scope of Art 4(1). The Court's view seems to have been based

largely on the administrative structure for care insurance. Note that the Court made every effort to include care insurance under Art 4(1) as otherwise it would fall into the problematic group of non-exportable contributory benefits (early retirement benefits are the main measures in this category).

In *Jauch*, the Court followed *Molenaar* by deciding that care insurance was a type of supplementary sickness benefit and therefore came under Art 4(1). However, there is no administrative link between care insurance and sickness insurance in Austria. It seems that the Court felt that it could not classify the Austrian scheme differently to the German scheme despite the administrative differences, as the nature of the risk covered was similar. However, the decision created a conflict with the decision in *Snares*, where the Court had confirmed that Disability Living Allowance (DLA) fell clearly within the scope of Reg 1247/92, and was validly listed by the UK as a non-exportable benefit under that regulation. There is very little difference between UK DLA and Austrian care insurance in the nature of the risk covered. The crucial difference between the two benefits is that DLA is tax-financed while the Court found the Austrian scheme to be contributory. The structure of the regulations has created an artificial situation in which contributory provisions for assistance with ADLs have come to be designated as sickness benefits when they fall more naturally under the rubric of specific protection for the disabled.

### **6.3 Definitions, Location and Mutual Recognition of Decisions**

#### *Assistance with ADLs*

While the contributory principle is the key idea behind exportability, there are also issues about whether rights are defined in ways which enable them to be exercised in any location, or whether some rights are inherently location-dependent. Reg 1408/71 makes a distinction between benefits in kind and cash benefits which can be seen as reflecting the reality of locational issues. Again, however, there is an issue about whether this distinction is an appropriate one for determining the exportability of provisions for assistance with ADLs, or whether this relatively new set of provisions requires a different approach.

Under Article 19(1) of Reg 1408/71, benefits in kind should be provided by the institution of the place of residence (the host state), in accordance with host state legislation. There are provisions for reimbursement by a 'competent institution', i.e. an institution which administered a social security scheme to which the person was subject when employed. Cash benefits may be provided by the competent institution in accordance with its legislation, i.e. cash benefits may be exportable.

Provisions for assistance with ADLs in the member states fall into three groups: provisions made only in cash, provisions which may be in kind or in cash, and provisions which are only made in kind (provision of services). Cash provision may take the form of standardised cash amounts, provided to the user with little control by funders on how the cash is spent ('fungible' cash provision). At the other end of the spectrum, cash may be paid to reimburse specific expenses, or the user may have a personal budget which can be used only for purchases approved by the funder ('non-fungible' provision). In the *Molenaar* case (C-20/96), the ECJ drew a distinction between cash *payments* and cash *benefits*. Cash must be fungible to be

regarded as a cash benefit. The key features of a cash benefit, in the view of the Court, are that periodical cash disbursements are made without being subject to specific expenditure having been incurred, and that the benefit therefore allows the person's standard of living 'as a whole' to be enhanced.

In *Molenaar*, the Court decided, on the facts, that the German scheme did provide cash benefits. Our view of the facts is that the German scheme falls very near the cash-kind borderline. Assessors are required to consider whether appropriate care can be provided before approving the cash option. A carer has to be nominated by the care recipient, for example in order to ensure that social insurance contributions are paid on behalf of the carer. Issues have been raised about the payment of the allowance when the nominated carer lives some distance from the applicant. Policy debates make it clear that the diversion of funds to general household expenses is a source of concern.

Austrian care insurance seems to be more clearly a cash benefit, as there is no in-kind option and less provision for checking how the money is spent. Similarly DLA in the UK is only provided in cash, and there are no checks on the use of the money. Examples of cash payments which are probably not cash benefits include personal budgets (PGBs) provided under the Dutch law on exceptional medical expenses (AWBZ). The budget is assessed individually on the basis of the person's needs and means (scope for co-payment is explicitly included). The person does have some freedom in using the budget, but it is monitored and issues can be raised about the pattern of spending. Other states, including Belgium (Flanders: direct payments scheme), Denmark and Sweden have experimented with cash options which are intended to allow the disabled person more autonomy in defining his or her needs than is achieved by traditional provision in kind, but these are almost undoubtedly cash payments rather than cash benefits, in the terms defined by the ECJ.

The issue for social security coordination raised by this diversity is whether the distinction between benefits in kind and non-fungible cash payments, on the one hand, and cash benefits, on the other, is a meaningful one. There are some differences between the different types of provision in the way needs are recognised and assessed. Cash benefit provision calls for standardised levels of benefit with standard criteria to determine which level of care needs a person has. All the provisions for assistance with ADLs discussed in this report use needs assessments as their primary instrument for determining entitlement. Usually (DLA in the UK is an exception), the assessor visits the person in the home and takes into account specific features of the home environment in determining the level of need. This common feature of provisions for assistance with ADLs would seem to suggest that entitlement is location-specific.

As noted above, Reg 1408/71 applies to cash benefits provided 'without any individual and discretionary assessment of personal needs, to recipients on the basis of a legally-defined position'. This wording is modelled around the distinction between social insurance and social assistance, and a number of benefits in the member states do not fall clearly into either category. In some states, national provisions for assistance with ADLs have partly taken over responsibilities previously met by local authorities as part of social assistance. In other states, notably in Scandinavia, responsibility continues to rest with local authorities but the rights of disabled people are more clearly defined than they used to be. In some states, the introduction of standardised amounts of provision is seen as the key to autonomy and rights, whereas in

others standardised provision is seen as weakening the responsiveness of the system to people's widely varying individual needs. Rights may instead be strengthened by defining the outcome (a certain standard of living) that a person should enjoy.

Exportability of benefits is still theoretically possible if entitlement is location-specific, and/or if rights are defined in terms of outcomes rather than fixed cash amounts. However, there can be no assumption that the disability assessment will be unaffected by a change of location. Generally, recipients of provisions for assistance with ADLs may be reassessed when their living circumstances change within their home state, and the same must hold for changes involving a move across borders. Provisions for assistance with ADLs are not structured as location-independent rights, even when standardised amounts of cash are provided. It is arguable that this is consistent with the social model, which draws attention to the role of environmental factors in determining the disabling effects of a person's impairments or limitations.

#### *Definitions in Benefits for Work Incapacity*

Under current coordination arrangements, most income maintenance incapacity benefits are exportable. Eligibility is determined by the competent institution: the insurance provider. Migrants cannot be required to travel to the state of the competent institution in order to be assessed, and a variety of mechanisms is adopted to arrange assessment in the state of residence.

Generally, member states rely on each other's institutions to provide the necessary information, and standard forms have been developed by an Administrative Commission to facilitate this. However, as the discussion in chapters 3 and 4 showed, different states are undoubtedly assessing different things when they administer their work incapacity benefits. The standard forms include standard medical data on diagnosis and impairment, along with a variety of work-related questions. The competent institution selects its relevant 'decision variables' from these data; two states may make different decisions about the degree of incapacity from the same data on the form. We can think of a person who works in several states as ending up with several different insurance policies, all insuring slightly different contingencies.

The discussion in previous chapters, and the information in Appendix 1, gives some insight into the reasons why there are these differences. The general idea of 'work incapacity' as a risk is recognised by all the member states, but the level and structure of insurance they offer differs for two main sets of reasons. States have different views about how best to maintain the legitimacy and integrity of their work incapacity insurance schemes, and states have different labour market objectives which influence their administration of their schemes.

It was shown in chapters 3 and 4 that states differ in the extent to which they aim to identify medical causes of a person's problems in the work environment. To some extent, these differences are correlated with the four different models of assessment described in chapter 4. These different patterns are partly connected with institutional structures (in particular, the relationship between health insurance and social security) and partly with the personnel involved. Different professions enjoy different levels of trust and prestige in the different member states. Furthermore, trust and prestige may be maintained in different ways: a high degree of specialist technical knowledge is one way; openness to scrutiny and debate is another (probably riskier) way. The difficulty with arguing that one model is 'better' than another is that the models are, at least in part, operated to maintain the legitimacy of the system, and changes in

approach run the risk of undermining the legitimacy of the decisions which determine eligibility and entitlement. Legitimacy has to be maintained not only in the eyes of the disabled people being assessed, who are most affected by the different approaches, but also in the eyes of contributors who need to have confidence that they will be covered if the relevant contingency arises. If governments take the view that their own assessment system is best tailored to achieve legitimacy in their state, then some degree of 'administrative nationalism' is inevitable.

It is well-established that the pattern of receipt of work incapacity benefits has been strongly influenced by labour market conditions, particularly among older workers. It was shown in chapter 3 that different states have adopted different approaches to the permeable boundary between incapacity, unemployment, early retirement and old age pension receipt. Some states have maintained a high normal retirement age with a high rate of incapacity benefit awards for older workers, while others have permitted more early retirement, with or without medical indications. These labour market policy decisions are also reflected in differences in the way labour market conditions are 'modelled' or imagined in the disability assessment process, and differences in the way that education, skills and other social factors influence the assessment.

Is it possible to perform an assessment without a model of the labour market and without taking social factors into account? An impairment-based barema could provide such a basis for assessment. It is striking that, in the recent Council of Europe study on assessing disability in Europe, the only proposal on the table for a standardised instrument of assessment was a 'European Barema'. The Council study group did not endorse this approach to assessment. It found that impairment baremas are more discretionary in application than they may appear, and furthermore they suffer from some major conceptual limitations, particularly when they attempt to measure the severity of an impairment without looking at its disabling effects.

A capacity-oriented approach like the UK's Personal Capacity Assessment (PCA) abstracts from labour market and other social factors. However, we would argue that there is an implicit model of the labour market in the PCA. The model is of a very flexible labour market in which any person who can perform a limited range of functions can find some sort of job, albeit possibly involving low pay and/or reduced hours. This implicit model of the labour market is clearly oriented towards the UK's labour market policy and market conditions, and it would not necessarily be appropriate to transplant the approach into a state with a different labour market structure. Furthermore, the model is supported by other related policies, notably the Disabled Workers Tax Credit, which are intended to supplement the low incomes of disabled workers.

It is arguable that a social model approach endorses the existence of an integral connection between the assessment of work incapacity and labour market conditions. The social model suggests that it is not meaningful to remove the concept of disability from its social context. This suggests that, where ability to work is the focus, it would not be appropriate to abstract from the labour market context and try to identify an 'essential' element in incapacity which could be applied across states and through time without adjusting for labour market conditions.

## Summary

This chapter has examined the conditions under which a disabled person in Europe may be able to migrate from one state to another and how migration is liable to affect access to benefits. Access may be achieved by exporting benefits from the home state or by exercising rights to non-discriminatory treatment in the host state.

Extension of rights of residence and non-discriminatory access to host state provisions are more likely to be effective in enhancing freedom of movement for disabled people than extending the exportability of benefits. The disabled people who have exportable rights are a select group, both in terms of work history (because many exportable benefits are insurance-based) and national origin (because only a small number of states have certain exportable benefits, particularly provisions for assistance with ADLs). However, there is considerable resistance among national governments to the Commission's proposal for a Directive on the right of citizens of the Union and their family members to move and reside freely within the territory of the Member States. These problems might be ameliorated by financial transfers between states, as is currently done in the coordination of benefits in kind. However, it is unlikely that free movement for disabled people will be achieved without greater convergence of economic conditions generally, and social provisions in particular, across the member states.

## DEVELOPING COMPARABLE DISABILITY DATA

The difficulties of comparing administrative data on disability across countries are well-known. Differences in social security provisions cause obvious problems. For example, some benefits are restricted by contribution conditions, and others by means tests. Some countries keep disability benefits in payment for the elderly, while others switch claimants onto old age pensions. There are great differences in the definitions used in employment provisions. Definitions may be impairment-based or activity limitation-based. Furthermore, we showed in chapter 3 that many states include some disabled people in a wider category of 'hard to place'.

### *Comparing Data on Employment Rates*

In our analysis of the definitions of disability used in employment provisions, we found that the number of people classified as disabled depended on the measures available and the personal and institutional incentives to use the classifications. One implication is that it is not possible to establish logical relationships between the definitions used in the European states that will enable us to say that one measure encompasses another or includes more employable people than another. These insurmountable problems are reflected in the recommendation of the European Expert Group on the Employment Situation of People with Disabilities that the EU should monitor the employment rates of disabled people by using survey rather than administrative data. While the surveys themselves are not necessarily strictly comparable (Gudex and Lafortune, 2000), a common activity limitation definition has been established: those reporting that they have a long-term health problem that limits them in daily life are counted as disabled. It seems to be widely accepted that this is an appropriate definition for employment measures, but the fact that it is different to the definitions used in employment policy administration does present some problems in deriving policy-relevant conclusions from survey findings. For example, many commentators argue that anti-discrimination policy should benefit people with impairments who are not limited in their employability: these benefits, should they occur, may not be detected in the monitored measure of employment among disabled people.

Another issue, which has arisen in the US debate on employment rates, is that the survey definition of disability will include many people who are not seeking employment. It is arguable that people who do not want employment should not be counted in evaluating the success of employment policies. This question is addressed in a recent US study which aims to resolve a controversy about the success or otherwise of the Americans with Disabilities Act (ADA) (Burkhauser *et al*, 2001). Burkhauser *et al* show that, as an empirical matter, the proportion of disabled people who are in the labour force (employed, job-seeking or available) has recently declined in the US as a proportion of all disabled people. Among those in the labour force, employment has risen, leading some commentators to argue that there has been an improvement in disabled people's employment rates in the US since the introduction of ADA. Burkhauser *et al* question this conclusion on the grounds that it is overlaid by the substantial decline in overall labour force participation. They see this decline as having policy significance as it suggests that the social environment has changed in a way which is adverse for disabled people seeking work. In effect, they accept that some disabled people may be

really unable to work or may prefer not to work, but they suggest that this group should be stable through time.

This argument implies that the employment rate of the whole population of people with disabilities is the appropriate variable to target, rather than the employment and unemployment rates of those who state themselves to be in the labour force. Labour force participation is itself liable to be influenced by member states' policies and labour market conditions. The reasons for monitoring the employment rates of the whole population of people with disabilities are similar to the reasons for monitoring the employment rate of the working age population generally, rather than the unemployment rate, which is susceptible to policy manipulation. Monitoring of overall employment rates is now established EU practice.

In our view, it is reasonable to use survey findings to monitor employment policies, but the possibility that the survey definition may include groups for whom employment policy is not relevant (e.g. those who do not want jobs), and exclude some for whom certain policies are relevant (e.g. beneficiaries of anti-discrimination policy) has to be borne in mind. Furthermore, when we move to other areas of policy, such as social security, the relevance of the survey definition of disability becomes more questionable.

#### *Comparing Data on Social Security Benefit Receipt*

OECD data suggest that there is a large disparity between the group of disabled people whose situation is reported in surveys and the group which is identified and targeted in social security measures. On average across the EU states for which data are available, about two-thirds of those who indicate that they have a long-term health problem that limits them in daily life (the survey definition) are not receiving an income maintenance disability benefit (OECD, 2002, Table 3.7). There is also a small group of people who are not classified as disabled on the survey definition but who nonetheless receive disability benefits. Comparing the survey definition of disability with definitions used in social security, we can identify two main sources of divergence:

1. Disability benefits providing income support or income maintenance do not generally examine whether a person is limited in activities of daily life. Instead, they examine whether a person is limited in the performance of work activities, sometimes described in a general way (e.g. in the German EMR), sometimes specifically referring to the demands of the person's last job (e.g. in the Italian AOI), and sometimes referring to specific possible jobs, whether abstractly described (e.g. as by the FIS database in the Netherlands) or concretely identified (e.g. through the step-by-step process in Sweden). It is possible for a person to be limited in activities of daily life and still be able to work, possibly with the aid of benefits, subsidies and adaptations. Similarly, it is possible for a person to be unable to work but to be able to perform his or her current activities of daily life, especially if these refer to a restricted set of activities.
2. Many social security and social protection benefits are paid in response to the needs arising from limitations in daily life, rather than because of the limitations themselves. In the case of provisions for assistance with ADLs, the relationship between limitations and needs would seem to be a close one: a person who is unable to perform core ADLs without help has a need for help. However, many states do not have provisions for which eligibility is defined in this way (and provisions for assistance with ADLs are not, in any case, included in the OECD

data). Other needs, such as the need for basic income support, do not necessarily flow from limitations in ADLs. Furthermore, as chapter 3 emphasised, some of the needs related to disability resemble needs arising from other causes and may be met by general provisions such as social assistance, or provisions targeted on a different group, such as early retirement benefits.

These limitations to the policy relevance of survey data suggest that it would be desirable to be able to understand and interpret national administrative data more readily, although the data will never be susceptible to direct comparison. This study has shown that, to understand the use of disability classifications in the member states, it is necessary to have information on the structure of particular provisions, along with an overview of the relationship between provisions. The appendices provide information about assessment methods, boundary issues and linkages between provisions in a standardised framework. In the following section, we consider how this information might be made available to policy-makers at the European level to facilitate comparison, debate and exchanges of best practice in an ongoing way.

#### *Future Monitoring of Definitions of Disability*

It would be possible to establish a reporting structure for disability provisions to ensure that more information on definitions of disability was available. At present, there is an annual reporting structure for social security provisions, the Mutual Information System on Social Protection in the Member States of the European Union (MISSOC) (available at [europa.eu.int/comm/employment\\_social/missoc2001/index\\_en.htm](http://europa.eu.int/comm/employment_social/missoc2001/index_en.htm)). MISSOC provides data relevant to disability in the following areas:

Chapter III: Sickness - Cash Benefits

Chapter V: Invalidity

Chapter VIII: Employment injuries and occupational diseases

Chapter XI: Guaranteeing sufficient resources - 2. Specific Non-Contributory Minima -

#### II. Invalidity

Chapter XII: Long-term Care

Detailed information is provided in MISSOC on contribution conditions, levels of benefits payable, whether benefits are taxable, accumulation with other benefits and so on. The country chapters also include the following information relevant to this project:

Basic principles: Explains whether the provision is tax-financed or contributory, means tested etc;

Field of application: Indicates who is covered (workers, self-employed, etc);

Risk covered: Here a definition is provided, e.g. that the worker cannot earn more than one third of normal earnings as a result of sickness or infirmity. Partial pensions are indicated. Age restrictions are also specified. However, information is not provided on the instruments used to assess whether a person meets the definition.

The new chapters on long-term care have a similar structure. Some useful basic information is given on the risk covered, e.g. that the person is not able to perform the basic activities of daily life. Age restrictions are noted, and under the heading of 'field of application', linkages with other benefits are noted (e.g. if care is only available to recipients of an income maintenance benefit), and the data indicate whether the scheme covers residents and/or contributors.

MISSOC therefore provides some of the information needed to be able to interpret administrative data, notably the age groups covered, whether there is partial disability, and whether means tests and contribution requirements operate. Only social protection is covered, so a number of measures related to the employment of disabled people are not included. In-work benefits for disabled people come under the heading of Specific Non-Contributory Minima, but subsidies paid to employers are not included. Employment promotion policies, quotas and other regulatory policies are not covered either.

While MISSOC is a very extensive database, it is not designed to enable researchers to understand the relationship between provisions. Nor does it provide more than the briefest account of the rationale for the structure of particular provisions. Such information requires a narrative account of disability policy. Member states currently provide narrative accounts of aspects of their social policies, particularly aspects related to employment promotion, under the open method of coordination. Narrative accounts of disability policy might be structured as follows. The reports could:

- identify policies where health indicators are used to define a target group;
- explain the rationale for definitions of disability used in these policies;
- summarise other allocative principles used, and thereby
- identify the role of the definition of disability in resource allocation.

This type of analysis could provide a framework within which information about developments in each member state can be collected and reported in a systematic fashion. The reports could also serve to develop common understanding of national strategies and facilitate exchanges of best practice.

Finally, we note that the Commission has endorsed the principle of 'mainstreaming' of disability policy issues. It has argued that, given that disabling effects arise from a wide range of environmental conditions, it is desirable to consider disability issues in the context of a wide range of policies, not just those where disabled people are specified as a target group. Clearly, monitoring mainstreaming presents a particular challenge, as no definition of disability is used. The success of mainstreamed policies might be monitored by using survey data, but this is subject to the limitations in the policy relevance of survey data noted earlier.

**PART IV**  
**CONCLUSION**

## CONCLUSION

This research project has reviewed the definitions of disability used in social security, employment and anti-discrimination policies. It has systematically collected information about definitions, covering methods of assessment, institutions and personnel as well as different policy understandings of what disability entails. The report outlines frameworks for interpreting definitions which may be used to contribute to debate and development in social policy. In s.8.1 we summarise the implications of some of the findings for understanding the use of disability classifications by the member states in their social policies.

Throughout this report, we have noted the importance of contingent elements in the disability categorisations used in social policy. Definitions are contingent in the sense that they are applied only in specific contexts, where particular personal, social and environmental factors are highlighted. The difficulty with a contingent approach is that it raises issues about how the boundaries between different sources of disadvantage are drawn, and highlights the problem of identifying the special and distinctive nature of disability as a criterion for the allocation of resources in social policy. Sometimes the distinctive descriptions of beneficiaries of different measures cannot be maintained, and the intended beneficiaries may overlap or compete with the beneficiaries of other measures. The assignment of people to categories may become susceptible to manipulation for financial or political reasons, undermining the moral relevance of the category. In s.8.2 we consider whether it is possible to create a more secure definition of disability for use in social policy which is less influenced by these contingent factors.

In s.8.3 we discuss the implications of our findings for disability politics. We argue that it is important to distinguish the social policy process of categorisation from the construction of group interests in politics and from the formation of group and individual identities. As was suggested in chapter 1, much of what the social model implies for definitions of disability refers to general social understandings of disability rather than processes of categorisation.

### **8.1 Disability Categories in Social Policy**

In chapter 3, we highlighted the impact of institutional integration and fragmentation on the use of disability categories. Social policy structures in which provision for different social policy categories (unemployed, disabled, retired) is integrated use disability classifications more flexibly than fragmented structures. In chapter 4, we showed that the states which used less medical approaches to disability also tended to have integrated institutional structures. There may be a causal connection between integration and the adoption of non-medical approaches, as the institution is not engaged in defending medically-defined boundaries. In systems where provision is fragmented, medical boundaries are more likely to be defended and doctors usually play a central role in assessment. As described in chapter 4, disability insurance providers in fragmented systems may also be health insurance providers and this may contribute to a heavy emphasis on medical data and maintenance of medically-defined borderlines.

The assessment of disability may be more or less discretionary. Integrated systems which are centralised tend to be oriented towards the use of instruments and rules designed to achieve consistency in decision-making. Medical data may be included in these instruments, in so far as it is seen as objective and reliable. A feature of these systems is that definitions of disability may be affected by central policy changes concerning the administration of unemployment benefits, (early) retirement provisions, and disability benefits. For example, tightened rules on job search and availability for work in unemployment benefit administration may lead to increased claims for disability benefits, and this may then give rise to changes in disability benefit administration which reflect aspects of the original unemployment policy change.

Where provision is fragmented but instruments of assessment are centrally legislated, definitions of disability are less susceptible to being influenced by changes in the social policy environment. These systems are often characterised by the use of impairment tables and baremas. We would expect assessment practices in these systems to be quite stable. However, there are issues about the policy relevance of the definitions of disability generated by these systems.

In each of the member states, different models of disability assessment are found in different areas of provision. The high medical evidence-low discretion model, involving the use of impairment tables or baremas, is widely found in regulatory policies, including quota schemes. It is less common in budgetary social policies, but is used in some states as an instrument of multi-level governance, where central government regulates provision by local or regional governments or insurance institutions. High-discretion models (both medical and non-medical) are more often found in areas of provision where control over policy and responsibility for financing are located at the same level of government. The low medical evidence-high discretion model is most often found in social assistance and employment service provision. In chapter 3 we noted that administrators often have considerable flexibility in classifying people as disabled for employment measures. Where a person's difficulties in getting a job are due to social as well as health limitations, mainstream measures may be more appropriate than special measures for the disabled. However, a number of states allow the Employment Service a larger budget for measures for jobseekers who are classified as disabled. Furthermore, targets for placement of disabled people may create an institutional incentive to designate people as disabled; in other words, to 'construct' disabled people.

## **8.2 Social Policy Definitions and Categories**

In chapter 3, we showed that disability was seen as entailing different things in different areas of social policy. In the area of income maintenance, disability is generally seen as entailing partial or total inability to work. In employment policy, disability may be seen as entailing reduced productivity, as an aspect of disadvantage in entering employment, or as a factor leading to discrimination in entering or retaining employment. In the provision of assistance with ADLs, disability can be seen as entailing extra costs of living and needs for care and support.

Some of these views about what disability entails have an affinity with a particular approach to assessing disability. This is most evident in the provision of assistance with ADLs, where the idea that disability entails extra costs and needs corresponds closely to the use of assessments oriented to the person's ability to perform activities of daily life. In other areas, it may be more

difficult to achieve *relevance* in the sense of conformity between what a policy envisages disability to entail and the method of assessment used for the administration of the policy. Finding an assessment of disability that is relevant to the risk of discrimination is clearly a problematic area, as discussed in chapter 5. One approach is to use an expansive definition (which hardly requires assessment) and focus on remedying discriminating situations as they arise. However, this approach cannot be used where a category definition is needed, as for the administration of positive action measures like quotas.

The discussion in chapters 3 and 4 also suggested problems with the relevance of some assessments in the fields of income maintenance and employment. In the income maintenance field, an assessment which looks primarily at a person's capacity to perform the tasks associated with gainful employment can be said to be relevant to the conception of what disability entails, but we have seen that the implementation of these assessments presents a number of difficulties. There is debate about what factors should be treated as relevant, e.g. whether age should be as influential in assessment as it appears to be, and how the assessment should reflect multiple and interacting disadvantages relating to disability, education and labour market opportunities.

Relevance would seem to be a fundamental requirement of an operable social policy category, but it is not the only requirement. It is clear from the examples given that relevant assessments will differ between policies, making categorisations inconsistent across policy areas. A person who is disabled for the purposes of an employment measure may not be disabled for provision of assistance with ADLs. This may not be 'wrong' in the sense that the person may face problems getting employment without concurrently having (sufficiently severe) limitations in daily life. However, multiple definitions and assessments do present some real problems. One problem is that a person may be 'circulated' between agencies, each of which has a particular idea of the target group for its programmes. A classic circulation problem arises when a person is 'too able' to work to qualify for disability income maintenance, but too disabled to be accepted by the Employment Service as available for work. This may mean that the person cannot receive unemployment benefit, and has then to look to general social assistance.

A related problem was emphasised by the OECD in its recent analysis of disability policies (see s.2.1). The study argued that a more 'coherent' policy mix was needed to promote alternatives to income maintenance policies. One of the main ideas put forward was that 'the term "disabled" should not be equated with "unable to work"' (OECD, 2002, para 25). The aim of this recommendation was that disabled people should be enabled to take up work more freely by ensuring that they did not lose their 'medical eligibility' for income maintenance benefits by working.

More generally, the idea of coherence suggests that it would be desirable to establish a disability status which allowed some freedom of action to the disabled person. This can be done to some extent by 'passporting' and linking eligibility conditions, but if it is to be done in a systematic way, potential conflicts between relevance and coherence arise. The issue is: what method of assessment could be used to establish a coherent disability status, and could such a status be relevant?

Our study suggests that there may be three candidates for this method of assessment. One (which is implicitly advocated in the OECD study) is a measure of work capacity which is

independent of whether the person is working or not. This single measure would determine the payment of both in-work and out-of-work benefits. Two states in the EU have developed abstract assessments of capacity (the UK and the Netherlands), but neither state has resolved the boundary problems between disability and unemployment arising from other sources of disadvantage. The states themselves do not show great confidence in their abstract assessments: it is still the norm to reassess a person's capacity if he or she takes up work (in the UK) or earns more than the assessment predicted (in the Netherlands).

The other two methods are drawn from outside the area of inability to work. When the OECD advocates that 'the term "disabled" should not be equated with "unable to work"', all the member states can point to at least one disability category in their social policy which complies with this suggestion. Most obviously, the assessment methods used for the administration of quotas do not equate disability with inability to work. As we have seen, quota assessments often try to identify an essential element of disability by using impairment as the basis for assessment. Impairment is also the basis for assessment in the states which have created disability cards to govern access to a range of provisions, or have established a single assessment instrument to be used across a range of provisions. However, as we saw in chapter 3, impairment rubrics do not escape the problem of relevance despite appearing to identify the essential ingredient of disability. The scope for meaningful direct measurement of impairment is very limited, with the result that the severity of impairments is often evaluated by looking to their disabling effects. Disabling effects arise in specific contexts, so the impairment assessment is not as 'essential' as it looks. A person may be rated as more severely impaired in one workplace than another, or as less impaired if at home than if working.

The other main area in which disability is defined without reference to ability to work is in provisions for assistance with ADLs, some of which provide benefits to workers as well as non-workers (in some states, more benefits are available to workers). The basis for assessment for these provisions is the person's ability to perform activities of daily life, which may be defined more or less broadly. As noted in chapter 7, survey definitions of disability also generally look for limitations in daily activities arising from a health condition. Could such a definition be used in social policy categorisation to achieve coherence without an excessive loss of relevance to specific policy concerns? The difficulty would be that a high threshold for limitations in daily life (only counting the most limited as disabled) would exclude some people with reduced work capacity who are eligible for employment measures and/or income maintenance, while a low threshold would open up the disability category in social policy to a lot of new members. We can deduce that this would happen by comparing survey and administrative statistics on disability.

A radical interpretation of these arguments might be that the use of disability categories in social policy is fundamentally compromised. If the categories are defined and assessed in a relevant way, they are not coherent, while the candidates for a coherent definition lack relevance to at least some of the specific concerns which social policies address. As we noted in chapter 1, one possible interpretation of the social model is that special disability categories should be eliminated, and rights and entitlements formulated in a general way as much as possible. However, we consider that the present discussion is not sufficiently complete to support such a view. Relevance and coherence are not the only principles behind the use of categories in social policy (Bolderson and Mabbett, 1991). The use of categories may enable social policy to avoid

more intrusive and problematic approaches to targeting resources to needs, such as means-testing. Categorisation may be part of the process of defending the legitimacy of the claims of particular groups. While there are a lot of issues and problems in the way disability is understood in social policy, the use of disability categories has brought some advantages which most would not want to abandon for the sake of a theory.

### **8.3 Categories, Identities and Constructions**

Following Jenkins (2000), we can distinguish between social categorisation and group identification. A category is defined and recognised by others; group identification occurs through self-recognition and mutual recognition among the group's members. Social categorisation may affect group identification because social categories affect the way people are treated in society, for example by social welfare agencies. The relationship between categorisation and identification is not straightforward, however: groups may rebel against and subvert the social categories that affect them.

Furthermore, we should not overstate the impact of social categorisation on group identification. As Jenkins points out, 'it is possible for people to belong to a social category without being aware of its existence, or their membership of it' (2000, p.13). He gives the example of census categories, developed and applied by social researchers to the 'raw' responses of individuals to questions. As discussed in chapter 6, survey definitions of disability are constructed *a posteriori* from answers to questions about health and limitations in daily life. The respondents probably do not know that their responses will be used to classify them as 'disabled'. Sometimes survey measures of disability are said to be based on 'self-definition', but this is misleading: they are based on self-reported limitations in daily life, not on self-defined disability.

The circumstances under which people do define themselves as disabled have not been much researched. We suggest that, even though people will often be aware of their social policy categorisations (their benefit status, etc), they do not necessarily adopt these categorisations as identities. One signal of the disjunction between categories and identities is terminological: the terms used for categories are frequently rejected as terms for identities precisely because their meaning is constructed by others, not by the identity group itself.

A small study by Watson (forthcoming) directly addresses the issue of self-identification as disabled. Most members of his sample of people with impairments demonstrated considerable resistance to adopting the identity of 'a disabled person'. Most of his respondents sought to establish social identities which were not dominated by their impairments: identities as members of families and friendship groups, as productive and skilful individuals, as people who led largely 'normal' lives. Whether one sees this as a genuine reflection of the limited importance of impairment or as a form of 'false consciousness' motivated by the stigma attaching to disability, the key point is that people should be able to develop and choose their own identities, not have an identity imposed upon them on the basis of some ascribed characteristic.

The politically-active informants in Watson's study also rejected an identity built on impairment, but they did identify with other disabled people in describing experiences of oppression. This suggests that the political mobilisation of a group with common experiences does not have to rest on defining a fixed and common identity. Political mobilisation could be

seen as involving a third process alongside the processes of identification and social policy categorisation. Following Schneider and Ingram (1993), we could call this process 'social construction'. Social constructions, in their analysis, are 'stereotypes about particular groups of people that have been created by politics, culture, socialization, history, media, literature, religion and the like' (1993, p.335). They argue that social constructions exert a strong influence on the formation of public policy.

In Jenkins's framework, social constructions are processes of categorisation, but for our purposes it is helpful to note the differences between social constructions and social policy categories. Constructions characterise groups of people but do not grapple with the task of determining which individuals precisely are in the group being described. Indeed, some difficulty in finding individuals who correspond to social constructions is inherent in their stereotypical nature. They often rely on anecdotes and selective analysis. There are clearly connections between social constructions and social policy categories: for example, rules defining categories may reflect concerns about excluding negatively-constructed groups such as 'scroungers' or including positively-constructed 'deserving' people, but these connections are often problematic because of the rhetorical nature of social constructions. The bureaucracy which administers categories may be influenced by this rhetoric, but equally it may be aware of dissonances between the constructed groups and the circumstances of the people actually encountered.

It is evident that much of the debate about the definition of disability is about the social construction of disability. It is concerned with how the public image of disability is shaped. This is very important to the development of disability policy. In the terms suggested by Schneider and Ingram's analysis, we can see how disability rights campaigners have put forward different social constructions of disability in the course of seeking to shake off the deserving but dependent image of disability in the public eye, and have promoted the development of new types of policy with different rationales to traditional social welfare measures. However, this study has also shown that innovations in the social construction of disability do not translate in a simple way into changes in the processes of social policy categorisation.

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