# DEFINITION OF DISABILITY IN EUROPE

## A COMPARATIVE ANALYSIS

Employment & social affairs



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### A COMPARATIVE ANALYSIS

A study prepared by Brunel University

## Employment & social affairs

Social security and social integration

#### **European Commission**

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#### **FOREWORD**

This comprehensive study which analyses and assesses the policy implications of alternative *definitions of disability* on policies for people with disabilities is highly relevant for all those interested in the future of collective action in favour of people with disability.

It clearly shows that the definition of what constitutes disability affects in particular the way that people with disabilities are regarded and treated by administrations and other organisations. Let us just take two examples drawn from the European context: different definitions can have important implications for the mobility of people with disabilities, and for their ability to take advantage of one of the elementary rights and founding freedoms of the Treaty – that of the free movement of persons; this freedom of movement becomes even more relevant in an enlarged Union of 25 Member States and in the context of increasing globalisation of economies and of societies.

The definitions and the criteria for determining disability that are laid down in national legislation and other administrative instances differ widely throughout the current 15 Member States. This can constitute a major obstacle to the mutual recognition of national decisions on disability issues, and in particular of eligibility for access to specific services and facilities. Thus, for example, within the European Union disabled people can face particular disadvantages in the field of social security and other rights as European citizens, when they move from one Member State to another.

It was against this background, that the Directorate General for Employment and Social Affairs commissioned this impressive study, produced by Brunel University. On the one hand, the study provides detailed country-by-country and benefit-by-benefit information about national policies which impact on people with disabilities or have a disability dimension, thereby providing an excellent research tool. On the other hand, and in my view of even greater importance, it gives a thought-provoking comparative analysis of those policies and the way in which definitions have influenced those policies.

The study also indicates some of the limits of the 'social model' of disability. This 'social model' treats disability in a more inclusive fashion than the former 'medical model' and moreover incorporates greater recognition of the 'rights' of people with disabilities. None the less, this 'social' model lacks a certain relevance to-day, given modern developments in disability policies, notably the increasing tendency towards mainstreaming, and a growing awareness of the benefits to be obtained by a more individualised approach.

A key message to emerge from this analysis is that the public authorities, including at European level, have an important role to play in shaping society in a fully socially-inclusive way, not least by formulating open inclusive definitions of disability. The study will undoubtedly make a significant contribution to policy follow-up to the European Year of People with Disabilities as it demonstrates that there is considerable scope for exchange of information and policy learning: the study clearly establishes that confusion and a lack of clarity concerning the basic concept of disability present major barriers to the drawing of comparative analyses and evaluations of disability policies and programmes within the European Union. Moreover, questions of definitions are crucial to the development of coherent policies in respect of disability, and to an understanding of how developments in this specific area interact with other relevant policy areas, such as anti-discrimination policies, income support programmes and overall labour market policies.

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#### THESE ARE THE ABBREVIATIONS USED IN THIS REPORT:

AAH Allocation pour l'Adulte Handicapé (Adult Disability Benefit - France)

ABW Algemene Bijstandswet (Social Assistance - Netherlands)

ACTP Allocation Compensatrice au titre de la Tierce Person (Compensatory

Benefit for those needing aid from a third person - France)

ADL(s) Activities of Daily Life

ADPA Allocation Départementale Personnalisée d'Autonomie (Personalised

Departmental Benefit for autonomy – France)

AF Arbetsförmedling (Employment Exchange - Sweden)

AFPA Association pour la Formation Professionnelle (Association for

employment training - France )

AGEFIPH L'Association Nationale de Gestion du Fonds pour l'Insertion

Professionnelle des Personnes Handicapées (National Association for the Management of the Funds for the Participation in Employment of Disabled

People - France)

AMA American Medical Association

AMS Arbetsmarknadsstyrelsen (Labour Market Board – Sweden)
AMSG Arbeitsmarktservicegesetz (Labour Market Service Act - Austria)

ANPE Agence nationale pour l'emploi (National employment service – France)

AOI Assegno ordinario di invalità (Ordinary invalidity grant - Italy)
ASL Azienda Sanitaria Locale (Local Health Agency – Italy)

AtW Access to Work (UK)

AWBZ Algemene Wet Bijzondere Ziektekosten (General Act on exceptional

medical expenses - Netherlands)

BA Bundesanstalt für Arbeit (Federal Employment Institute – Germany)

BA Benefits Agency (UK)

BeinstG Behinderteneinstellungsgesetz (Disabled Persons Employment Act -

Austria)

BIZ Berufs-Informations-Zentrum (Careers Advice Office – Germany)
BPGG Bundespflegegeldgesetz (Federal Attendance Allowance Act – Austria)
BSB Bundesministerium für Soziale Befreiung (Federal Office for Social Affairs –

Austria)

BPA Brukerstyrt personlig assistanse (Self-directed Personal Assistance -

Norway)

BWA Blind Welfare Allowance (Ireland)

CAA Constant Attendance Allowance (Ireland)

CAT Centres d'aide par le travail (sheltered workshops – France)

CCI Certified cause of incapacity (Ireland)

CCAS Centre Communal d'Action Sociale (Municipal centre for social affairs -

France)

CERMI Comité Español de Representates de Minusvalidos (Spanish Committee of

Representatives of Disabled People)

COTOREP Commission Technique d'Orientation et de Reclassement Professionnel

(Technical Commission for Employment Information and Guidance -

France)

CPAM Caisse Primaire d'Assurance Maladie (Local Sickness Insurance Fund –

France)

DCODP Danish Council of Organisations of Disabled People (Denmark)

DDA Disability Discrimination Act (UK)
DEA Disability Employment Advisor (UK)

DLA Disability Living Allowance (UK)
DMG Decision Makers Guide (UK)
DPTC Disabled Persons Tax Credit (UK)

DRASS Direction Régionale des Affaires Sanitaires et Sociales (Regional Office for

Health and Social Affairs - France)

DSFCA Department of Social, Community and Family Affairs (Ireland)

DWP Department of Work and Pensions (UK)

EMR Erwerbsminderungrente (Benefit for reduced earnings capacity – Germany)

ES Employment Service

ETP Etablissements de travail protégé (places of protected employment -

France)

EVI Equipos de Valoración de Incapacidades (Offices for assessment of

incapacity – Spain)

FÁS Foras Áseanna Saothair (National training and employment authority -

Ireland)

GdB Grad der Behinderung (Degree of disability – Austria and Germany)

GP General Practitioner

GRTH Garantie de ressources des travailleurs handicapés (guarantee of

resources to the disabled worker – France)

IADL Instrumental Activities of Daily Life

IB Incapacity Benefit (UK)

ICD-9 International Classification of Diseases, 9<sup>th</sup> revision ICD-10 International Classification of Diseases, 10<sup>th</sup> revision

ICIDH-I International Classification of Impairment, Disability and Handicap (1st

version, 1980)

ICPC International Classification of Primary Care

IEFP Instituto do Emprego e Formação Profissional (Institute for Employment

and Training – Portugal)

IKA Idrima Kinonikon Asfalisseon (Social Insurance Institute – Greece)

IMSERSO Instituto de Migraciones y Servicios Sociales (Institute of Migration and

Social Services - Spain)

IMS Informe Medico de Síntesis (Summary medical report – Spain)

INAIL Istituto nazionale per l'assicurazione contro gli infortuni sul lavoro (National

Institute for Workers Compensation - Italy)

INPS Istituto Nazionale della Previdenza Sociale (National Institute for Social

Protection - Italy)

INSS Instituto Nacional de la Seguridad Social (National Institute for Social

Security - Spain)

ISSA International Social Security Association

KK Krankenkassen (Sickness insurance funds – Germany)

LAS Lagen om anställningsskydd (Employment Protection Act – Sweden)

LASS Lagen om assistansersättning (Law on Assistance Compensation –

Sweden)

LCPDE Law on Compensation to Persons with Disabilities in Employment

(Denmark)

Ley General de la Seguridad Social (General law on social security – Spain)
LISMI Ley de integracion social de los minusválidos (Law on the social integration

of disabled people – Spain)

LISV Landelijk Instituut Social Verzekeringen (National Institute for Social

Insurance – Netherlands)

LSP Law on Social Pensions (Denmark)
LSS Law on Social Services (Denmark)

LSS Lagen om stöd och service till vissa funktionshindrade (Law concerning

Support and Service for Certain Groups of Disabled People – Sweden)

MISSOC Mutual Information System on Social Protection in the EU Member States

and the European Economic Area

MPs Medical Panels

MPT Majoration pour Tierce Personne (Increase for [care by] a third person –

France)

MRA Medical Review and Assessment (Ireland)

MTAS Ministerio de Trabajo y Asuntos Sociales (Ministry of Work and Social

Affairs - Spain)

NDA National Disability Authority (Ireland)
NDDP New Deal for Disabled People (UK)
NGO Non-Governmental Organisation

NHS National Health Service

NIA National Insurance Act (Folketrygdloven - Norway)

NRB National Rehabilitation Board (Ireland)

ONCE Organización Nacional de Ciegos de España (National Organisation of the

Blind of Spain)

PAYE Pay-as-you-earn (UK and Ireland)
PCA Personal Capability Assessment (UK)

PEO Public Employment Office

PGB PersoonsGebonden Budget (Person-linked budget - Netherlands)

PSD Prestation Spécifique Dépendance (Specific benefit for dependency -

France)

PVAng Pensionversicherung für Angestellte (Pension Insurance Agency for White

collar Employees - Austria)

REA Wet (Re)integratie Arbeidsgehandicapten (Work Handicapped

(Re)integration Act – Netherlands)

RFV Riksförsäkringsverket (Social Security Board – Sweden)

RMI Revenu Minimum d'Insertion (minimum participation benefit - France)

Rmistes Recipients of RMI (France)

RSV Richtsatzverordnung (Ordinance setting out guiding principles [for

determining the percentage of disability] - Austria)

SHD Sosial og helsedepartementet (Social and health department - Norway)

SII Social Insurance Institution (Finland)

SoL Socialtjänstlagen (Social Services Act – Sweden) SSA Social Services Act (Sosialtjenesteloven - Norway)

TBA Terugdringing Beroep op de Arbeidsongeschiktheidsverzekering (Act on

Reducing Disablement Benefit Claims – Netherlands)

TH Travailleur handicapé (disabled worker – France)

TSG Tax Strategy Group (Ireland)

uvi Uitvoeringsinstelling (Administrative office of social insurance -

Netherlands)

VM Valoración de las situaciones de minusvalía (Assessment of situations of

disability - Spain)

VNG Vereniging van Nederlandse Gemeenten (Association of Dutch

Municipalities - Netherlands)

WAGW Wet Arbeid Gehandicapte Werknemers (Disabled Workers Employment

Act - Netherlands)

Wajong Wet Arbeidsongeschiktheid Jonggehandicapten (Invalidity Insurance

Young Disabled Persons Act - Netherlands)

WAO Wet op de Arbeidsongeschiktheidsverzekering ([Act on] Disability benefit -

Netherlands)

Waz Wet Arbeidsongeschiktheid Zelfstandigen (Invalidity Insurance Self-

employed Persons Act – Netherlands)

WEA Work Environment Act (Norway and Sweden)

WHODAS II World Health Organization Disability Assessment Schedule II

WIW Wet Inschakeling Werkzoekenden (Jobseekers Employment Act -

Netherlands)

WSP Working and Social Profile (Italy)

WSW Wet Sociale Werkvoorziening (Sheltered Employment Act – Netherlands)
WVG Wet Voorzieningen Gehandicapten (Provisions for Handicapped People

Act – Netherlands)

#### Appendix 1

#### Austria

Berufsunfahigkeit = incapacity to pursue own occupation

Erwerbsunfahigkeit = *incapacity to earn* 

Pensionversicherung für Angestellte = pension insurance agency for white collar employees

Pensionverischerung für Arbeiter = pension insurance agency for blue collar workers

Allgemeinen Sozialversicherungsgesetz = General Social Insurance Law

Gewerblichen Sozialversicherungsgesetz = Social Insurance for Proprietors [self-employed]

Bauern-Sozialversicherungsgesetz = Social Insurance for Farmers

vorzeitige Alterspension wegen geminderter Arbeitsfähigkeit= Early old age pension on account of reduced working capacity

Leistungskalkul = calculation of capacity to work

#### **France**

Pension d'invalidité= Invalidity pension

Allocation pour l'Adulte Handicapé = Adult Disability Benefit

Caisse Primaire d'Assurance Maladie =Local Sickness Insurance Fund

médecin contrôleur = *controlling doctor* 

Caisse Régionale d'Invalidité = Regional Invalidity [Pension] Fund

Travailleur handicapé = Disabled worker

carte d'invalidité = disability card

Ministère de l'emploi et de la solidarité = Ministry of Employment and Solidarity

une retraite anticipée pour inaptitude au travail = early retirement due to unsuitability for work

#### Germany

Erwerbsminderungrente = Pension for reduced earnings capacity

#### Italy

Pensione di inabilita= Pension for inability [loss of 100% of work capacity in any occupation] Assegno mensile = monthly grant [for those whose working capacity is reduced by at least 74%]

#### Netherlands

Wet op de Arbeidsongeschiktheidsverzekering= [Act on] Disability benefit

#### Spain

Equipos de Valoración de Incapacidades = Offices for assessment of incapacity

#### Appendix 2

#### Austria

Grad der Behinderung = Degree of disability
Richtsatzverordnung = Ordinance setting out guiding principles

#### Germany

Sozialamt, Jugendamt = social welfare office, youth welfare office

Pflicht zur Beschaeftigung schwerbehinderter Menschen = obligation to employ severely handicapped people

Gemeinsame Servicestellen fuer Rehabilitation = joint facilities for rehabilitation

Berufs-Informations-Zentrum = careers advice office

Versorgungsamt = care office

Amt fuer Versorgung und Familienfoerderung = office of care and family support Länder = states

#### Italy

Commissione provinciale per le poliche del lavoro = Provincial committee on employment

#### Appendix 3

#### France

Majoration pour Tierce Personne = *Increase for [care by] a third person* 

Allocation Compensatrice au titre de la Tierce Person = Compensatory Benefit for those needing aid from a third person

Allocation Départementale Personnalisée d'Autonomie = *Personalised Departmental Benefit for autonomy* 

Prestation Spécifique Dépendance = Specific benefit for dependency

#### Germany

Sozialamt = Social office

#### Italy

permissi in favore di persone gravemente handicappate = rights for the benefit of severely handicapped people

#### Portugal

Ministério do Trabalho e da Solidariedade = Ministry of Labour and Solidarity

### **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 co-ordinate 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 co-ordination 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

#### Chapter 1 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 co-ordination', 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 chapter 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 chapter 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 crossnational 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 co-ordination 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 co-ordination was relatively straightforward, as the relevant regulations and ECJ decisions set out the factors which are considered relevant to co-ordination. 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 <u>straightforward</u> 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 'problematising' 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 'Iname 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, have 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 ageing, 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' ageing 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.

#### **Chapter 2** 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 'recognises' 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 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... Terms 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 co-ordination, 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 recipiency 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 recipiency 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 recipiency rates. The OECD study explores a number of ideas about how disability decision-making affects benefit recipiency, 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 recipiency 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/govn/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(Activities of Daily Life) (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 co-operating 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

# **Chapter 3** 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 inabilities 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 'laisser 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 (Disability Living Allowance) 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' ageing (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 ageing 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 meanstested 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 noncategorical 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 judgement 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 a health-related early retirement (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 <u>abstract</u> 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 pyschological 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 <u>required</u> to seek work. Administrative guidance often uses the formulation that the person should be <u>'treated as</u> 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 minusvalía' (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(Commission Technique d'Orientation et de Reclassement Professionnel) 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 " Industrial Injuries and Occupational Disease Provisions" 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 noncategorical 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 co-ordination to the insurance 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 non-categorical 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*(Social assistance) Individualised assessment is a central principle in the administration of Social assistance, 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(Social assistance) 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 Revenu Minimum d'Insertion (RMI) as well as an assistance measure for disabled people Allocation aux Adultes Handicapés (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 duration 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 dead-weight 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 guota 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 non-categorical 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 (non-categorical 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.

# **Chapter 4** 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 judgements 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 judgements 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 judgement 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 <u>attempted</u> 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 judgement 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 policyholders 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

# Chapter 5 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 I 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 (Judgement 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) 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 ageing, 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 the Association nationale de gestion du Fonds pour l'insertion professionnelle des personnes handicapées, 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 common-sense 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 <u>any</u> 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.

## **Chapter 6** 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 EEC N° 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 EC 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 EEC Regulation N°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 Regulation 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 Regulation 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 Regulation 1408/71, or provided specific protection for the disabled. Regulation 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 Regulation1247/92.

The relationship between the two classes of risk - those covered by Article 4(1) of Regulation 1408/71 and those mentioned in Regulation 1247/92 - raises some interesting issues in the area of disability. Invalidity benefits are listed in Art 4(1), while Regulation 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 Article 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 Article 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 Article 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 Regulation 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. Regulation1408/71 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 Regulation 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(European Court of Justice) .

The issue for social security co-ordination 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, Regulation 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 co-ordination 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 eachother'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 co-ordination 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.

## **Chapter 7** 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, jobseeking 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 <u>work</u> 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 policymakers 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). 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 co-ordination. 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**

## **Chapter 8** 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, socialisation, 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 dissonance 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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## **APPENDICES**

## Appendix 1 The assessment of incapacity or inability to work

The payment of pensions or benefits to people found to be unable to work due to 'incapacity' or 'invalidity' constitutes one of the largest areas of provision for disabled people in the Member States, both in terms of numbers of recipients and expenditure. All the Member States have at least one income support or income replacement measure for this category of people. In the following summary, we describe these measures very briefly (under the heading <u>Provisions</u>) in order to establish the context in which the decision on inability to work is made. Provisions may include contributory pensions, non-contributory benefits, and/or means-tested benefits. In some countries, these different provisions use a common definition of inability to work; in others, there are variations in definition. Some social assistance provisions use a definition of disability which is related to care and/or mobility needs rather than work ability: these are not included here. Also excluded from this summary are industrial injuries and occupational disease schemes.

The country-by-country summaries are organised as follows. The definition of disability is described in three main ways: the stated definition in the law governing the provision, the process of entry into the system and the assessment protocols used. The headings are:

Provisions

Decision to be made

Process of becoming unable to work; employer's responsibilities; rehabilitation Assessment

- diagnosis
- impairment
- standardised descriptions of physical or mental capacity
- standardised descriptions of working life
- standardised descriptions of daily life
- job abilities or requirements specific to the person
- personal and social circumstances specific to the person

Following this, two important areas of background information are included:

Institutional structures and personnel Permeability of boundaries: age, social disadvantage.

Under the latter heading, brief information is given about the relationship between the invalidity pension system and the old age pension system, and, where relevant, about other benefits. Controversies and issues about boundaries raised in the national reports are also noted here.

This Appendix includes an Annex on Standard Classifications of Medical Diagnoses and Impairments (p.58) and References (p.60). All information relates to 2001, when the national reports were being written. Where applicable, changes introduced before 1 Jan 2002 are noted.

#### **AUSTRIA**

#### **Provisions**

The main provisions for workers who become disabled are the *Berufsunfähigkeits*-, *Invaliditäts*- and *Erwerbsunfähigkeits*- pensions. These are contributory benefits. Those without a contribution record are reliant on general social assistance, *Sozialhilfe*(Social assistance) to meet their income needs.

Provisions on *Berufsunfähigkeit* relate to white collar workers and are administered by the *Pensionsversicherung für Angestellte* (PVAng). The detailed discussion below refers to this institution. Provisions on *Invalidität* relate to blue-collar workers and are administered by the *Pensionsversicherung für Arbeiter*. The definition of disability in each case is similar and is found in the *Allgemeinen Sozialversicherungsgesetz* (ASVG).

Provisions on *Erwerbsunfähigkeit* are found in the *Gewerblichen Sozialversicherungsgesetz* (GSVG) and *Bauern-Sozialversicherungsgesetz* (BSVG), applying to proprietors and farmers respectively.

#### Decision to be made

Berufsunfähigkeit: a white-collar worker, who (in the last 15 years) has mainly worked (for more than half of the time) in the occupation he was trained for or has acquired skills for is deemed invalid if, because of his physical or mental state, his earning capacity has been reduced to less than 50% of a healthy person's earning capacity who has a similar education and work experience. This reference to a comparable job is termed Berufsschutz ('job-protection').

A worker who has mainly worked in occupations other than the occupation he was trained for or has acquired skills for is deemed invalid if, because of his physical or mental state, this person will no longer be able to earn at least half of the income when performing any activity whatsoever which a healthy person could earn performing this activity. In place of the reference to earning capacity in a comparable job, the reference is to potential income, termed *Einkommensschutz* (earning-protection).

Invalidität: The definitions correspond to those for Berufsunfähigkeit but apply to manual workers. Thus, a blue-collar worker who (in the last 15 years) has mainly worked (for more than half of the time) in the occupation he was trained for or has acquired skills for may be deemed invalid on the same definition as a white-collar worker (see the first part of the definition above). A worker who has worked in other/ unskilled jobs is subject to the definition in the second paragraph above.

There are several provisions allowing early retirement. Early retirement on grounds of incapacity is provided by the *vorzeitige Alterspension wegen geminderter Arbeitsfähigkeit*. A worker is eligible for this pension on the grounds of reduced capacity for work at age 55 for women and age 57 for men (the same for manual workers and white-collar workers) if, because of his/ her physical or mental state, he/she is no longer able to earn half of the income which an insured healthy person regularly earns performing such an activity, if this activity has been performed for more than 50% of the time during the last 15 years and if the reduced capacity for work has existed for at least 20 weeks. In practice, the difference between this provision and the others concerns the extent to which a change in employment may be required: older workers are not expected to exhibit flexibility in this regard.

There is no partial pension.

#### Process of becoming unable to work; employer's responsibilities; rehabilitation

Sickness benefits are paid for up to 26 weeks, extendable under some conditions (relating to contributions history). A disability claim can be filed at any stage during the sickness period. Initial awards of disability pensions are normally for two years, although some permanent awards are made.

The principle of 'rehabilitation before pension' has been legally grounded in Austria since 1996. In practice this means that part of the budget of the insurance institution can be devoted to the maintenance of rehabilitation institutions and meeting rehabilitation expenses, although there is no fixed target or share of expenditure devoted to rehabilitation. At any time, about 5% of the caseload of the PVAng is in rehabilitation measures.

#### Assessment

- diagnosis
- impairment

Generally, there is considerable emphasis on getting a full description of the person's medical condition. Reports may be commissioned from specialist doctors (either employed by the insurance agency or from external doctors on a case-by-case basis). Additional inpatient examinations may be conducted, usually at the insurance agency's own rehabilitation clinics or hospitals.

However, there are some cases where an award can be made on the basis of a person's application and supporting medical documentation alone. This possibility is reserved for very serious diseases, especially terminal conditions.

#### - standardised descriptions of working life

In the *Leistungskalkul* the doctor answers a series of questions about what general work conditions are 'reasonable' for the person without taking into account age and previous work experience. These general work conditions include e.g. hours of work, shifts, environmental factors etc.

#### - job abilities or requirements specific to the person

The applicant must describe his or her predominant profession of the last 15 years precisely, on the application form, for the purposes of the *Berufsschutz*.

The question of how the person's ability to work is affected by his or her condition is not taken up in the specialist medical reports; it falls to the doctor doing the overall medical report to formulate a view about the applicant's capacity to do his/her job.

#### Institutional structures and personnel

The assessment may involve detailed medical inquiries. Diagnoses may be revisited, reflecting the integration of health care provision with cash support.

More than half the applications for *Berufsunfähigkeitspension* at the PVAng are rejected. The appeals process reflects the social partnership foundation of social insurance, with lay judges representing the employers and trade unions sitting alongside the legally-trained judge. About half of those whose applications are rejected appeal, but only a quarter of these are successful in having their appeal sustained or getting a settlement.

#### Permeability of boundaries: age, social disadvantage.

Invalidity pensions are aligned with the old age pension and cease to be paid when the person becomes eligible for the old age pension. In addition to the provisions on early retirement due to invalidity, there are other provisions allowing early retirement for older unemployed workers and workers with a full contribution history. These provisions come into play from age 55 (women)/ 60 (men), although these ages are gradually being increased.

The national report suggests that the Austrian system is marked by strict medical control, although social factors intervene for older workers.

#### **BELGIUM**

#### **Provisions**

The two main income support provisions for people unable to work due to injury or illness in Belgium are the insurance-based invalidity pension (*indemnité d'invalidité/invaliditeitsuitkering*) and the non-contributory income replacement allowance for the disabled (*allocation de remplacement de revenus/ inkomensvervangende tegemoetkoming*). There is in addition a general social assistance scheme (the *Minimex*). In practice the recipients of the non-contributory income replacement allowance are likely to be those who also receive an 'integration' allowance relating to care needs and social contact.

## Decision to be made

#### For invalidity pension:

A person is considered to be incapacitated for work when he/she has suspended all work activity as the direct result of the appearance or the aggravation of injuries or functional impairments which have been recognised as limiting his/her earning capacity to 1/3 or less than what a (non-disabled) person of the same social class and with the same education and professional training can earn

- in the same category of occupations to which the occupation belongs which the person was exercising at the moment when he/she became incapacitated during the period of 'primary work incapacity' which may last for up to one year, or
- in all the occupations which the person has been able to or could perform in accordance with his/her education and professional training after one year (or sooner if the condition has stabilised) when long-term invalidity is being assessed.

There is no partial incapacity. It is possible to combine some income from work with receipt of the pension if approved by the *médecin conseil* (doctor advising the insurance institution) as part of the process of a progressive return to work.

For income replacement allowance for the disabled:

A person is entitled to this allowance when his/her physical or mental condition results in a diminution of earning capacity to 1/3 or less what a non-disabled person might earn in any job on the general labour market.

#### **Invalidity Pension**

## Process of becoming unable to work; employer's responsibilities; rehabilitation

A claim for invalidity pension may begin from paid employment, self-employment or unemployment. Initially a person who is unable to work or not available for work due to ill health receives a benefit for 'primary work incapacity', which can last for up to one year. Wage continuation from the employer lasts one month at most; by the end of this period the *médecin conseil* should be informed and will conduct an examination. The *médecin conseil* may authorise a partial return to work and investigate rehabilitation options. Both medical and vocational rehabilitation can be financed by the health insurance provider.

The *médecin conseil* may consider that a person is not prevented from work due to sickness and refer him or her to unemployment insurance. Otherwise, if the claim continues for more than six months, an application for invalidity pension will be prepared.

#### Assessment

#### - diagnosis

The *médecin conseil* performs a standard medical examination. If s/he has any doubt about the records provided by the person's own doctor, the diagnosis may be revisited.

No disease or impairment automatically gives access to the benefit; nor does lack of a clear diagnosis preclude access.

- standardised descriptions of physical or mental capacity

'What matters is the presence of functional limitations which limit work performance' (Belgian report, p.8). However, no standard instruments are used to identify functional limitations.

### - standardised descriptions of working life

In principle, the assessor should calculate the 'residue-earnings' which represent the amount a person could earn in an occupation which he or she could perform despite the incapacitating limitations and is in accordance with his or her education and professional training. However, there are no instruments for making this hypothetical assessment, so the estimation of whether the residue earnings fall above or below the critical threshold of one-third of normal earnings is a matter for the judgment of the assessor.

# - job abilities or requirements specific to the person

The degree of loss a person has suffered is assessed relative to the earnings of a similar person without the incapacitating condition: in practice, the previous earnings of the person provide the benchmark.

### - personal and social circumstances specific to the person

In practice, the assessment is specific to the person as the central question concerns a claimant's prospects of successful reintegration into the labour market. If the limitations in job prospects faced by the claimant are not due to functional limitations (but to e.g. poor general labour market conditions or poor work orientation) then the claimant may be referred to unemployment insurance. However, there is no precise measurement of the extent to which prospects are reduced by functional limitations versus job availability.

### Income replacement allowance:

## Process of becoming unable to work; employer's responsibilities; rehabilitation

Generally applicants for this allowance have never worked or have only worked irregularly, and have no other source of income.

#### Assessment

#### - diagnosis

Doctors employed by the Ministry of Health conduct the examination and make their own diagnosis, and also use records of other assessments.

- standardised descriptions of physical or mental capacity

There is no official functional listing.

#### - standardised descriptions of daily life

The evaluation is often done in conjunction with an application for integration allowance, for which an extended ADL scale is used.

# - job abilities or requirements specific to the person

The lack of work experience of those being assessed means that even less information is available with which to evaluate work capacity than for the insurance-based invalidity pension. The doctors do not have good access to information on labour market options and chances.

### Institutional structures and personnel

The *médecin conseil*, who controls access to insurance-based pensions, is not the person's treating doctor. If the medical circumstances are very clear (e.g. the person is in hospital) he might not do an examination, but he will always see the person at some stage. He may collect the results of medical examinations done by other doctors and he can also ask for new examinations.

While the *médecin conseil* is not involved in decisions about acute health care provision, he has an important role in the provision of rehabilitation. The médecin conseil makes proposals for rehabilitation programmes and will consider the cost of medical rehabilitation or a re-training programme, which has to be centrally approved by a committee of doctors at the Ministry (with local branches in the regions).

Income replacement allowance: the doctors who do the assessment for this are employed by the Ministry of Health. They are engaged solely in assessment for benefit purposes and not at all in health service provision.

### Permeability of boundaries: age, social disadvantage

Invalidity pensions cease at retirement. Old age pension age is currently 61 for women (rising), 65 for men; however many invalidity pension recipients can utilise early retirement provisions for those with sufficient work history from age 60.

Textual analysis of cases brought before the Labour Courts suggests that personal factors such as age, sex, level of education, personality and attitude affect the decision on invalidity pension.

#### **DENMARK**

### **Provisions**

The Law on Social Pensions (which dates from 1921, but was substantially extended in 1965 and reformed in 1984, with further changes in 1998) provides for three levels of early or before-time pension (*førtidspension*). The medium førtidspension can be awarded when a person's 'vocational ability' is reduced by at least two-thirds due to a medical condition; the highest pension where his or her remaining vocational ability is negligible. The lowest level (*almindelig førtidspension*) is awarded when the claimant's working ability has been reduced by at least half for medical <u>and/or social</u> reasons. All the benefits are non-contributory. *Almindelig førtidspension* is means-tested against all income when it is awarded for social or social-medical reasons. All the pensions are subject to reduction against wage income.

#### Decision to be made

The social *almindelig førtidspension* can be awarded to a person who is long-term unemployed where vocational rehabilitation measures or active labour market policies are exhausted. Because it is not essential to show that a health condition is present and playing an important part in the person's prospects, this basic pension is not solely a disability pension.

The medium and higher pensions, and the medical *almindelig førtidspension*, refer to reductions in 'vocational ability', which is understood as referring to the impact on ability to do a job of a person's health condition. In determining the extent of the reduction some regard is paid to education and earlier job, age, location and possibilities of employment. By contrast, 'working ability' (the term used in the context of the social *almindelig førtidspension*) is defined as 'the ability to fulfil the demands that are imposed in the labour market to do different specified tasks in order to gain an income for complete or partial self-provision' as assessed in the vocational rehabilitation process (Danish report, p.6).

'Vocational ability' is a different, and older, concept to 'working ability'. It is planned that by 2003 criteria will be unified in an approach based on working ability.

### Process of becoming unable to work; employer's responsibilities; rehabilitation

Employers finance the first two weeks of sickness benefits; responsibility then moves to the public system, administered by the municipalities. Sickness benefits are usually payable for up to a year, but this may be extended, particularly for those awaiting vocational rehabilitation, but, as explained further below, the municipalities have strong incentives not to extend the 'passive' benefit period. Generally sickness benefits end when a doctor certifies that the person's medical condition has stabilised.

As a general rule, employers may dismiss a worker after 4 months of sickness absence (Høgelund, 1999, p.18).

Another route onto *førtidspension* is via social assistance. Long-term unemployed people on social assistance may also be directed towards vocational rehabilitation (including e.g. remedial education). Entry into rehabilitation is not based on medical criteria.

The municipality considers the award of a disability pension when possibilities for rehabilitation and employment (including sheltered employment) are exhausted. Formally the claimant does not apply for the pension: it is proposed by the municipality as the last option.

### Assessment

#### - diagnosis

The interpretation of 'vocational ability' which has been established through time is strongly linked to the medical diagnosis. Conventions have been established (although not formalised in a list) about how certain medical diagnoses affect a person's vocational ability.

However, the intention of the reforms in progress is to move away from an 'essentialist' diagnostic approach. Diagnosis-based awards are criticised on the grounds that a person's potential work ability is not explored. Employment policies have been adopted (such as the Law on Compensation to Disabled Persons in Employment - see Appendix 2) which are intended to support people with severe conditions in employment.

- standardised descriptions of working life

The definition of 'working ability' refers to 'the demands that are imposed in the labour market to do different specified tasks'. However, there is no standardised listing of tasks. Instead, the assessment is made on the basis of experiences in the course of the vocational rehabilitation process.

#### - standardised descriptions of physical or mental capacity

Alongside 'working ability', the concept of 'functional reduction' has been developed to capture medical aspects of reduced ability. The term 'functional reduction' is used to describe the practical effects of a diagnosis.

# - personal and social circumstances specific to the person

Section 15(3) of the Law on Social Pensions states that: 'In the assessment of the extent to which the applicant's working capacity is reduced, a comparison shall be made between the likely income from any employment which corresponds to the strength and skills of the applicant and which, in view of his or her education/training and occupational background, may be expected from the applicant, and the normal income of a person having undergone similar education/training in the same region. Other factors such as age, occupation, address and employment prospects should also be considered, as should any other factors which may be deemed to be important in the given circumstances.'

In practice, the interpretation of these factors may come down to the municipality's success or otherwise in finding a job which the person can function in.

# Institutional structures and personnel

The devolution of responsibility for decision-making on disability pensions means that there are variations between municipalities in the procedures followed. For example, for a person whose claim begins with a period of sickness benefit, a standard form is used for sickness certification but municipalities decide how frequently to request certification (doctors are paid a fee for providing certificates). When deciding whether to award a disability pension, the municipal case worker makes decisions about what specialist medical reports to obtain (and the municipality pays for them). However, it would be wrong to imply that the municipality controls the medical information available. Sometimes the claimant's own doctor is perceived as acting as an advocate for the claimant. The medical reports are reviewed by a municipal doctor (who does not, however, examine the claimant himself – he is a 'paper doctor'). Disputes about the interpretation of specialist medical evidence are one of the reasons for appeals.

# Permeability of boundaries: age, social disadvantage

Førtidspension ceases when the old age pension age of 65 (for both men and women) is reached. For people over 60, the lowest rate of førtidspension is aligned with the old age pension (although the means test is more rigorous). Thus the low rate which, as noted, is based on social as well as medical grounds, provides a route to early retirement.

Institutionally, the system tends to blur the relationship between disability and other sources of disadvantage. The municipalities administer social assistance, sickness benefit and vocational rehabilitation schemes as well as the førtidspension. They are required to undertake 'activation' for social assistance recipients. The financing structure means that municipalities have financial incentives to keep people in activation or rehabilitation. Municipalities are reimbursed 50% by the state for social assistance/ activation and rehabilitation benefits, whereas the *førtidspension* is reimbursed at only 35%. Rehabilitation benefit can last for a maximum of 5 years. Sickness benefit is refunded to 50% for one year; after that it is a municipal expense without any refund. The very best outcome for the municipality is to get the person into a job. The 'flexjob' scheme (discussed in the appendix on employment measures) provides that 50% or 67% of the wage is paid by the state, with no expenses (other than the administrative cost of setting up the placement) for the municipality.

#### **FINLAND**

#### **Provisions**

Finland has a national pension system covering the whole population, along with a contributory employee pension system (and some private voluntary provision). About two-thirds of disability pension recipients receive benefits from both systems; others receive only a national pension because of insufficient contributions, or receive the partial employee pension (national pensions are only payable for 'full' incapacity to work).

#### Decision to be made

Law on National Pension: A person is considered disabled if he/she is, because of sickness, impairment or injury, not able to perform his/her usual work or other corresponding work, which must be considered appropriate and secures reasonable income taking into account age, qualification and other relevant factors. (Finnish report, p.12).

Employees' Pension Law: An employee is entitled to disability pension if his/ her working capacity can be estimated as lowered by at least 2/5, continually for at least a year, due to sickness, impairment or injury.

Those whose capacity is lowered by 40-59% can receive a partial pension; the full pension is awarded for those whose capacity is lowered by 60%+.

In estimating the lowering of the working capacity, the administering institution must take into account the employee's remaining capacity by which he/she can earn an income in an available job by performing work that can reasonably be expected taking into account his/her education and training, previous activity, age and housing conditions plus other corresponding relevant factors. (Finnish report, p.12).

Thus there are two provisions with different decisions to be made which are, however, often administered in parallel. The disability-related requirements of the Employees' Pension Law appear less stringent than those of the National Pension, but people with inadequate insurance cannot receive the Employees' Pension. The institutions administering the two pensions are legally bound to consult each other when awarding or rejecting an application.

### Process of becoming unable to work; employer's responsibilities; rehabilitation

The process of being awarded a disability pension usually starts with a period of short-term sickness benefit receipt, which lasts for a maximum of 360 days. Sickness benefits are administered by the Social Insurance Institution (which administers the national pension). The benefit payable was previously called temporary disability pension but is now called 'cash rehabilitation support', and its payment should be accompanied by the development of a rehabilitation plan (although this does not always happen in a meaningful way in practice).

As well as providing vocational rehabilitation, the SII can also provide compensation to a disabled person in work for costs related to help, services etc. This benefit, called the employment-related disability allowance, is payable at three rates depending on the severity of the disability.

Medical care is provided by the health service, which is institutionally separate from SII. However, SII also funds medical rehabilitation (ASLAK). SII is required to spend a proportion (4%) of sickness benefit expenditure on rehabilitation.

#### Assessment

## - diagnosis/ impairment/ descriptions of capacity

Sickness certificates contain a diagnosis and the doctor's certification that the person is unable to work. When an application for disability pension is made, the medical certificate certifies the disability by giving a diagnosis and a (usually lengthy) account of the working incapacity. This account may contain a description of how the person is functionally impaired by his or her medical condition.

When a person is unemployed before becoming sick, a different view is taken of 'work that can reasonably be expected'. After an initial spell of vocational protection, an unemployed person is expected to accept a very wide range of job offers. The medical certificate in this case is framed in more general terms, indicating that the person's condition limits his or her scope for work in general, rather than relating to the specific demands of the occupation.

For National Pension, 'social' disabilities such as alcoholism are not <u>per se</u> sufficient to qualify: there must be other relevant factors. These may be diagnostically-oriented (e.g. medical complications) or functionally-oriented (e.g. ability to do basic physical or mental tasks and actions).

### Institutional structures and personnel

The medical certificate for disability pension is provided by the person's own doctor. Medically-trained experts employed within the SII/Employee insurance institutions assess the medical certificate and application form.

The recommendation of the medical expert is very influential, but final decision is made by insurance clerk. 'Internal' appeals to the SII/ insurer are heard by a board comprising the initial decision-makers (medical expert and clerk) plus representatives of the employers and trade unions etc. External appeals to the Administrative Court are also possible.

### Permeability of boundaries: age, social disadvantage

Disability pensions cease when a person reaches the age limit for the old age pension (65 for men and women). 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 parttime pension can be drawn from age 58 with evidence of reduced earnings.

Those with low employability are likely not to be eligible for an Employee Pension due to lack of work history/ contributions. If the claim begins when person is unemployed, a wide view is taken of possible work (see above).

#### **FRANCE**

#### **Provisions**

There are two main income support provisions for people unable to work due to illness or injury in France: the insurance-based *pension d'invalidité* and *Allocation pour l'Adulte Handicapé* (AAH), which is a social assistance measure. Work incapacity is assessed in different ways for the two benefits, by separate institutions. AAH pre-dates the general social assistance system, Revenu Minimum d'Insertion (RMI), which was introduced in 1988. The introduction of RMI led to a discussion about the rationale for AAH and other categorical assistance benefits. RMI provides for each recipient to have a contract of insertion' which should take his or her particular needs into account. This raised the question: "would there still be a need for special legislation on disability, or, conversely, should the handicapped person not be treated like any other citizen?" (Alfandari, 1997, p.684) In the end, AAH was retained, but a survey of *Rmistes* in 1998 found that one-third stated that they had disabilities which limited their ability to work or restricted activities of daily life (Afsa, 1999, p.3). Furthermore, since the application process for AAH is lengthy while that for RMI is quick, RMI can be used as an interim benefit (Colin et al, 1999, p.7).

#### Decision to be made

#### Pension d'invalidité

To be declared as an invalid, the individual must not be able to find a job which allows him or her to earn more than one third of the wage that a individual would receive in the same area, in the same category of work which he had before.

There are three categories of invalidity:

Category one: the individual is still able to do some work.

Category two: the individual is unable to work in any occupation.

Category three: the individual is unable to work and needs the aid of a third person to help in daily life activities.

The pension for Category 1 invalidity is 30% of the average wage (calculated from the best 10 of previous years); category 2 50%.

#### **AAH**

Adults who do not meet the contribution requirements for participation in the insurance system (the SECU) may claim AAH, which requires an assessment from COTOREP as well as a means test. The person must be assessed as 80%+ disabled by COTOREP, or as 50-79% disabled and unable to get a job on account of his or her disability.

#### Pension d'invalidité

### Process of becoming unable to work; employer's responsibilities; rehabilitation

For insured workers, sickness benefits (*indemnites journalières*) are payable for up to three years for those with long-term or chronic conditions (otherwise, for a maximum of 360 days in three years), but the decision to seek *pension d'invalidité* may be made before the end of the three year period if the health condition of the individual is stabilised and unlikely to improve (*consolidé*). The long duration for which sickness benefits are payable is accompanied by controls within the sickness benefit system which in other countries would govern the transition from sickness to invalidity benefits. Specifically, sickness is initially certified by the treating doctor, but checks operate after 3 months, and at the 6 month point, the certification must be confirmed by the *médecin conseil* (doctor advising the insurance institution) at the *Caisse Primaire d'Assurance Maladie* (CPAM). Checks operated by the CPAM are concerned with the management of health care treatment costs as well as cash benefit costs.

The employment contract of a sick worker is suspended for the duration of the illness, but cannot be terminated by the employer without going through certain procedures. An amendment to the Labour Code in 1990 established that the dismissal of a worker on the basis of invalidity alone is prohibited. Before dismissal can occur, the worker must be assessed by a work doctor (*médecin du travail*) who certifies whether the worker is unable to do his or her current job and makes recommendations about possible alternative jobs within the organisation or changes to the job (e.g. part-time work). While the employer does not have to accept the work doctor's recommendations, he must have good cause for rejecting them.

It is possible to return to work from sickness on a part-time basis with part-payment of sickness benefits. There must be a 'therapeutic' reason for this option, and the employer must agree. The maximum period for this arrangement is six months.

The decision to apply for invalidity pension is largely in the control of the doctors involved. Potential beneficiaries may apply themselves but this is not usual nor recommended. If the *médecin conseil* decides against an award of the pension because the condition is not stabilized, this may be appealed to an expert who is agreed between the person's own doctor and the *médecin conseil*.

#### Assessment

- diagnosis

For sickness benefits, the treating doctor must indicate precisely the medical justification for stopping work.

- job abilities or requirements specific to the person
- personal and social circumstances specific to the person

Commentaries on invalidity pension determination emphasise that the reduction in the capacity of the policy-holder is not based on the person's condition itself, but on the consequences of that condition for the person's ability to undertake remunerative work. According to the law, eligibility is determined not only by the gravity and the nature of the affections or infirmities noted, but also by the age of the subject, his or her physical and mental capacities, vocational training and prior work activities (Art.L 341-3 Code S.S.). The concept of invalidity therefore takes account of medical criteria but also criteria of a professional and social nature at the same time.

However, it is important to note that the *médecin conseil* is directed to look at the person's potential for employment in the whole local labour market. This contrasts with the assessment of 'aptitude' or 'inaptitude' made by the médecin du travail (work/ occupational doctor), which is directed to a person's ability to perform a specific job (possibly with adaptations). It is therefore possible for a person to be found 'inapt' by the work doctor without being found 'invalid' by the insurance doctor. Equally, the classification of (general) invalidity does not rule out the possibility of the person undertaking a specific job. This distinction has been developed in employment law, where there is a debate about whether a determination of invalidity constitutes grounds for the employer to dismiss a person without going through the process of assessment by a work doctor and consideration of alternative work (the process of determining 'aptitude' or 'inaptitude'). Guidance from the Ministry of Labour suggests that a determination of invalidity should not be taken as automatic grounds for dismissal (Circulaire DRT no 94-13, 21 Nov 1994). The médecin du travail may be called upon to assess the possibility of a partial resumption of work for a person assessed in the first category of invalidity, and in some circumstances may also investigate a return to work for a person in the 2nd category.

#### **AAH**

#### Assessment

In effect, the assessment involves two parts: first the assessment of percentage of handicap (which falls into 3 bands: A (0-<50%), B (50-<80%) and C (80%+)), and, second, the decision about whether a person in Band B is unable to work.

The 'guide bareme' which forms the basis for COTOREP assessments refers explicitly to the WHO concepts of impairment (déficience), disability (incapacité) and handicap (désavantage social). The bareme indicates rates of disability resulting from impairments. In other words, for most impairments, the extent to which an impairment is deemed severe is evaluated by looking at its effect on (dis)ability. (Exceptions are sensory impairments, which are evaluated directly.) In the terms used in the Introduction, the French bareme looks at 'disabling effects' rather than attempting to measure the percentage of disability directly from the impairment. As also noted in the Introduction, the use of an impairment framework means that a rule is needed for adding up the effects of several impairments. (the Belshazzar formula is used). However, it is emphasised that this rule is only indicative in nature.

- diagnosis
- impairment

The headings in the Guide Bareme are very similar to the impairment listing in ICIDH-1. However, the form for the medical report by the treating or other doctor uses different headings. (The medical report is important: two-thirds of applicants are not medically reexamined.)

The headings on the medical report are:

Intellectual impairments and/or psychological troubles and/or behavioural difficulties

Impairments relating to epilepsy

Hearing impairments

Impairments of speech and language

Vision impairments

Cardio-respiratory impairments

Impairments of the digestive system

Urinary system impairments

Metabolic or enzymatic impairments

Blood and immune system impairments

Musculo-skeletal impairments

Disfiguring impairments

- standardised descriptions of physical or mental capacity
- standardised descriptions of daily life

In the medical report, the consequences of impairments are described in terms of spheres of autonomy, rated A (able to do totally, habitually and correctly), B (can do partially, non-habitually, not correctly) or C (cannot do at all). The spheres are:

Coherence: able to converse and comport him/herself in a logical and intelligible manner

Orientation: knowing the time, intervals in the day, and place

Personal hygiene

Dressing

Eating: able to eat a prepared meal

Continence

Transfers: able to get up, lie down and sit

Moving around inside the home: with or without a stick, walking frame or wheelchair

Moving around outside the home: able to go out without means of transport

Communication at a distance: able to use telephone, pager or alarm

These headings are more precise and specific, and more oriented towards concrete activities, than the headings in the Guide Bareme, which are concerned with orientation, behaviour, communication, autonomy and social relationships. The Guide Bareme also includes, in some fields, a more detailed rating than the A, B, C rating.

## - job abilities or requirements specific to the person

The initial medical report also indicates the effect of the handicap on the person's ability do his or her current job, noting the arrangement of the workplace, hours of work, difficulties, mobility, absenteeism.

The Guide Bareme does not include any employment-related items, either specific to the person or framed in general terms. There is little indication as to how COTOREP makes the decision as to whether a person rated as 50-79% disabled is unable to get a job on account of his or her disability. A study in 1999 showed that those with higher rates of disability (8/10 of those with 70% disability but 4/10 with 50%) were more likely to be found to be unable to get a job (Colin et al, 1999, p. 6). Older women were one of the groups more likely to be seen as unable to get a job.

# Institutional structures and personnel

For the invalidity pension, the médecin conseil makes a medical determination. The final decision is taken by the *médecin contrôleur* of the *Caisse Régionale d'Invalidité*, on this guidance. Health care provision and cash support are integrated: the CPAM and its regional counterpart are responsible for control of the health care costs incurred by treating physicians as well as the benefit costs that their recommendations about resumption of work give rise to.

The assessment by COTOREP is based on an interpretation of the concept of disability in ICIDH-1. In principle, the assessment looks at the impact of impairments on the 'whole person' and then makes an appropriate 'orientation' recommendation (to mainstream employment, sheltered employment etc). Medically-trained professionals are joined by work psychologists, social workers and labour experts in making these assessments. The technical team makes its recommendations to a lay commission, which comprises representatives of the social partners, health, employment and care service providers, and representatives from disabled people's organisations. The Labour Code provides that the disabled person can put his or her case in person and discuss the possible decision with the Commission.

In practice, meetings of the Commissions have become rather infrequent and appearances by disabled people themselves occur more often on appeal than at first decision. Furthermore, the COTOREP doctor or a doctor acting for COTOREP only examines the claimant in about one-third of cases. Many cases are, therefore, decided on the basis of the documentary record.

COTOREP has two sections, the first dealing with employment orientation and according the status of *travailleur handicapé*; the second dealing with social benefits such as AAH. On the application form, the claimant indicates whether they are seeking measures relating to employment (*insertion professionnelle*) or a benefit or a card do not have to address the first section or have an assessment as a handicapped worker. Coordination between the two sections is limited; the former has traditionally reported to the Ministry of Employment and the latter to the Ministry of Social Affairs. Although these two ministries were combined in 1997 (into the *Ministère de l'emploi et de la solidarité*), the separate sections at the level of the Department remain. This is rather significant for AAH, where the second section does the assessment even though the eligibility of people classed as 50-80% disabled depends on an assessment of their work prospects.

# Permeability of boundaries: age, social disadvantage

The pension d'invalidité is payable to people aged between 20 and 60; beneficiaries are transferred to the old age pension system (régime de la Pension Vieillesse) at age 60. 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 "a health-related early retirement " (une retraite anticipée pour inaptitude au travai) 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 job-specific incapacity (inaptitude) rather than the general concept of incapacity used in the administration of long-term sickness and invalidity benefits.

Since 1999, recipients of AAH are also transferred into the old age pension system at 60.

From 2000, handicapped workers who are in work under special terms can retire at the age of 57.

#### **GERMANY**

#### **Provisions**

The main provision for income support for people with reduced capacity to work in Germany is *Erwerbsminderungrente*, EMR. This is a contributory insurance benefit. Social assistance is also available to people with disabilities but the tests of disability for social assistance revolve around care and mobility needs rather than work incapacity.

### Decision to be made

EMR is payable to people who have a completely or partially reduced capacity to earn a living as a result of 'illness or disability' (*Krankheit oder Behinderung*).

Complete incapacity is defined as inability to work more than 3 hours per day; partial incapacity envisages a residual ability to work 3-6 hours per day.

## Process of becoming unable to work; employer's responsibilities; rehabilitation

A person who becomes ill when working is initially entitled to six weeks' wage continuation, payable by the employer. Responsibility then shifts to the sickness insurance funds (*Krankenkassen*, KKs), which pay 80% of the wage for up to 78 weeks. The KK may request that the sick person applies for EMR during this period if it regards his or her health situation as long-lasting, and the claimant has 10 weeks in which to do this. The KK finances medical rehabilitation as well as paying health care service costs.

The KKs assess incapacity to work (*Arbeitsunfaehigkeit*), i.e. the assessment of incapacity is conducted in relation to the person's last work/job. By contrast, the assessment for EMR is of the person's incapacity to earn a living (*Erwerbsunfaehigkeit*), i.e. the assessment of the person's overall capacity in relation to the general labour market.

An application for EMR is treated as an application for rehabilitation, and rehabilitation options must be investigated prior to the award of long-term benefits.

In principle, an employed person who becomes less able to work, without experiencing the onset of a critical illness causing him or her to stop work, should be assisted by the rehabilitation services of the pension funds (the KKs might not be involved).

#### Assessment

# diagnosis

Sickness certification is undertaken by the treating doctor (home or hospital doctor). When the application for EMR is made, the treating doctor provides a report indicating the diagnosis, current complaints, the background to the illness, the current treatment, results of medical examinations and other medical findings (weight, height, blood pressure, test results etc) and the history and duration of the illness.

Should the Medical Service of the pension institute decide that an examination of the claimant is required, a medical report is commissioned which may revisit the diagnosis. The diagnosis is coded according to ICD-10 in this medical report and an additional coding is provided for indicating the symptoms of the condition, whether it is chronic or recurring, etc.

### - impairment

The treating doctor's report contains space for description of 'functional limitations' but there is no listing of what these might include.

Medical reports commissioned by the insurance funds also contain an open heading for functional limitations, with specific headings to indicate if the person is: deaf, blind, mentally handicapped, wheelchair user.

### standardised descriptions of working life

The fund's medical report includes a 'social medical assessment' in which the person's capacities in the general labour market are indicated. This *Leistungsbild* includes so-called positive and negative elements.

Under the positive elements are included assessments of capacity to do:

do heavy/ medium/ fairly light/ light work

stand, sit, walk - all/ some of the time

work shifts - day/ evening or night.

Under the negative elements are included assessments of the person's:

medical/ psychological ability to deal with work requiring

concentration, adaptiveness, flexibility, responsibility, contact with the public.

sensory capacities: seeing, hearing, speaking...

posture and agility: use of hands, bending, walking up steps, carrying.

The assessment also indicates conditions which would be dangerous to the person: dampness, draughts, temperature variations, factors leading to allergic responses, noise, frequently changing times of work.

Note that there is some overlap with the standardised descriptions of physical or mental capacity found in other countries' schemes. It is not clear exactly what the rationale is for the division between 'positive' and 'negative' elements. The positive elements could be seen as standard possible work conditions, while the negative elements arguably envisage a range of job demands which may relate to the problems a person has.

This assessment concludes with the doctor's view of how many hours a person could work, although the time bands are not the same as for partial and full EMR.

The medical expert making the summary recommendation on medical eligibility uses detailed guides which describe the impact of medical conditions on a person's potential performance in the world of work. Considerable emphasis is put on consistency between the diagnostic account of a person's medical condition and the account of the person's limitations in the labour market, using these guides.

#### - job abilities or requirements specific to the person

On the claim form, the claimant indicates his or her educational and professional history. The degree of loss a person has suffered is assessed relative to the earnings of a similar person without the incapacitating condition.

When the medical assessment indicates partial incapacity, the fund must establish that appropriate work is available; otherwise a full benefit must be paid. At present, part-time opportunities are seen as being very limited (the part-time labour market is 'closed') and therefore a full payment is generally made. This practice conforms to a key decision of the Social Court.

# Institutional structures and personnel

The German system is marked by the involvement of highly-qualified experts and the collection of a lot of information. The assessment process is often lengthy. The integration of health care provision with cash support means that those involved in assessment for cash benefits can call for further medical procedures and tests to be undertaken.

However, the system is also marked by a complex allocation of responsibilities for medical and vocational rehabilitation between the KKs, the Pension Insurance funds, and the Employment Service. Various government measures have called for greater co-ordination between these institutions. The most recent initiative is the establishment of 'joint service centres' which will inform disabled people about benefit eligibility criteria and identify the competent fund for arranging and financing rehabilitation.

Technically, the final decision on EMR is made by an administrative legal specialist, but the medical assessment is almost always accepted. The administrative officer addresses the question of whether commensurate job opportunities are available to those offered a partial award (see above on the part-time labour market).

The medical expert who formulates the overall decision on medical eligibility potentially has access to an extensive file of medical reports, but does not meet the applicant him/her self. Considerable emphasis is placed on achieving consistency in decision-making, through the documentation of the medical basis for decisions and through the use of the guidelines, which are updated regularly in the light of Social Court decisions.

# Permeability of boundaries: age, social disadvantage.

Early retirement provisions: Workers with sufficient years of insurance can retire before the official age of 65: men at 63, women at 60. Workers who have been unemployed for a year can retire at age 60.

As noted above, the assessment process for EMR can be lengthy, and options relating to rehabilitation are explored as well as medical issues. The process appears to be able to respond flexibly to the different needs and circumstances of those who claim. However, internal flexibility is accompanied by institutional rigidity, with ongoing issues about the assignment of responsibility and competence between the various institutions. These institutional divisions create boundaries which may go some way to explaining how the number of people receiving EMR is restricted.

#### **GREECE**

#### **Provisions**

The main provisions for people unable to work due to invalidity in Greece are:

- employee pension schemes, including the general scheme, IKA, and the schemes for public sector workers;
- insurance schemes for farmers and the self-employed, who make up a large part of the Greek labour market;
- noncontributory social assistance for those unable to work with special needs and special programmes for particular medical conditions.

The respective insurance schemes also encompass work injury and occupational disease provisions. The determination of the degree of disability under these provisions is the same: differences arise in the contributions record necessary to receive a pension and in the provisions for accumulating other income along with the pension. Furthermore, the Health Committees which determine the degree of 'medical' disability (see below) also determine whether there is a sufficient link between the workplace and the injury/ disease and/or the resulting impairment to qualify for the work injury and occupational disease provisions.

#### Decision to be made

The main insurance scheme is the employee scheme, IKA. IKA allows for:

- partial invalidity (50-<67%)
- invalidity (67-<80%)
- severe invalidity (80%+)

whereas the other insurance schemes only provide for invalidity (67%+).

In the IKA scheme a person assessed as 100% invalid receives an extra 50% allowance to pay for care by another person.

The legal definitions of invalidity for IKA refer to earning capacity as the basis for the different percentages of invalidity, i.e.

- severe invalidity (80%+): person cannot earn from work corresponding to his strength, skills and education more than 20% of what a comparable healthy person could earn;
- invalidity (67%+): person cannot earn from work corresponding to his strength, skills and education in his usual professional activity more than one third of what a comparable healthy person in the same professional category could earn;
- partial invalidity (50%+): person cannot earn from work corresponding to his strength, skills and education in his usual professional activity more than one half of what a comparable healthy person in the same region and professional category could earn.

However, despite the references to earning capacity and the adaptation of different degrees of invalidity to different criteria about profession and region, the actual assessment appears to be very much dominated by medical criteria.

## Process of becoming unable to work; employer's responsibilities; rehabilitation

IKA provides sickness benefits for insured people with illnesses certified by the person's own doctor.

#### Assessment

#### - diagnosis

Determinations under IKA are divided into two parts: 'medical' invalidity, which refers to the identification of the medical condition and the degree and duration of impairment, and 'insurance' invalidity, which refers to the assessment of the reduction in earning capacity. The determination of medical invalidity is undertaken by Health Committees. Their decision may be appealed to a higher Health Committee but must be accepted by the insurance authorities.

There is a range of specific provisions ('shortcuts') for certain diagnoses and conditions, e.g. for IKA (provided sufficient working days accrued): paraplegia and tetraplegia, thalassemy (Mediterranean anaemia), blindness.

For social assistance, there are special provisions for those with: blindness, spastic encephalopathy, thalassemy or AIDS, Hansen's disease, deaf-mutes, paraplegia and tetraplegia, severe mental retardation (IQ < 30) etc. Within the general provisions for assistance to those certified by a Certification Committee (see below), there is a shortcut for those with kidney disease and diabetes.

#### - impairment

The Guide for the Evaluation of the Disability Rate (1993) is applied by Health and Certification Committees. It presents scales and ranges for the determination of the degree of disability resulting from specified medical conditions. It is divided into chapters based on areas of medical specialism:

internal pathology skin and subcutaneous tissue psychiatric and neurological orthopaedic ear-nose-throat surgical eye and adnexa occupational diseases

The chapters are divided under different diagnostic headings. In some cases, e.g. injuries to limbs (musculo-skeletal impairments) and eye/ vision problems, detailed scales are given for the exact measurement of the degree of invalidity.

## - job abilities or requirements specific to the person

The Guide does allow for the determination of the degree of invalidity to be influenced by the work that the person normally does, e.g. whether the job is intellectual or manual. Some specific occupations are indicated as limited by specific impairments, e.g. driver or painter in the case of loss of colour differentiation. In making determinations for IKA, the committee is concerned with assessing the degree of <u>loss</u> since the commencement of work/ insurance. This allows particular occupational effects to be taken into account. It also means that pre-existing conditions (e.g. from childhood) may not result in a high degree of invalidity.

## - personal and social circumstances specific to the person

In particular parts of the Guide, the Committee may also take into account:

- individual characteristics such as age and gender, e.g. the Guide indicates different degrees according to age for impairments of the upper limbs;
- education: when assessing intellectual retardation, the Committee looks at the level of education achieved;
- social factors: effects on social integration, social links and autonomy are mentioned in specific places (e.g. drug addiction, mobility impairments).

In addition to the incorporation of these factors into the determination of 'medical' invalidity, the insurance authorities may raise the percentage of invalidity determined by the Health Committee by up to 17% (to take account of labour market or other social factors).

#### Institutional structures and personnel

The IKA Health Committees (which make decisions on 'medical' disability) are separate to the Health Committees of other insurers and from the Certification Committees formed by the Ministry of Health and Social Care for the administration of the Disability Card and related provisions, including social assistance. However, the same doctor can serve on several committees and in some cases other insurers use the IKA committees.

## Permeability of boundaries: age, social disadvantage

The old age pension age is 65 for men and 60 for women (latter is rising).

Various early retirement provisions exist for those with sufficient contributions, also for those who have worked in arduous or unhealthy work or in the construction industry. Different provisions are in force for those entering insurance after 1.1.1993.

While the self-employed and farmers can enter the insurance system, the high proportion of the workforce with non-employee status in Greece suggests that many will not be covered by insurance benefits and instead will rely on social assistance. There is no general social assistance scheme in Greece. Social assistance has traditionally only been provided for those with certain specified disabling medical conditions. Some elements of a more general disability scheme were put in place by laws in 1989 and 1995, but coverage focuses on special needs rather than lack of income due to inability to work.

#### **IRELAND**

#### **Provisions**

In Ireland there are two income support benefits for people whose work capacity is permanently reduced by illness or impairment: a contributory Invalidity Pension and a non-contributory and means-tested Disability Allowance. The short-term contributory sickness benefit (payable for up to a year) is currently called Disability Benefit. There is a proposal to rename it Sickness Benefit, and to introduce a non-contributory sickness benefit also, but this has not been implemented.

# Decision to be made

The decision to be made on disability for each benefit is slightly different, although the assessment procedures are very similar. For Invalidity Pension, a person must have been continuously incapable of work for at least a year (receiving short-term Disability Benefit), or permanently unfit for work, or over age 60 and suffering from a serious illness or incapacity. (Thus, for people with very serious conditions or people over 60 with serious illnesses or incapacities, Invalidity Pension may be paid without the full intervening 12 months of Disability Benefit payments.)

'Incapable of work' means incapable of work by reason of some specific disease or bodily or mental disablement, or deemed, in accordance with regulations, to be so incapable. There are no partial awards.

For Disability Allowance, a person must be 'medically suitable' (as well as passing a means test). A person is medically suitable if s/he has: 'an injury, disease or illness or has a physical or mental disability, which has continued or may be expected to continue for at least one year. As a result of this condition, s/he is substantially handicapped in undertaking work which would otherwise be suitable for a person of his/her age, experience and qualifications.'

These definitions are reproduced in the guidance notes for the Medical Review Assessment (MRA), but no indication is given about how the decision might differ in practice as a result of the different wording of the conditions. The same MRA form is used for the different benefits.

## Process of becoming unable to work; employer's responsibilities; rehabilitation

Disability Benefit is payable after three 'waiting days' when an employee becomes sick. There is no statutory sick pay payable by the employer although employers may pay sick pay or operate wage continuation payments under collective or individual agreements with workers. There are no statutory duties on employers to facilitate a sick person's return to work. The possibility that such duties might be implied by the prohibition on discrimination against disabled people in the Employment Equity Act (1998) has not been tested. Disability benefit provides the pathway to Invalidity Pension (see above).

The non-contributory Disability Allowance, which was introduced in October 1996 and replaced Health Boards' Disabled Person's Maintenance Allowance, begins with certification by the claimant's own doctor, acting as 'medical certifier'. On the claim form, the doctor indicates diagnosis and medical history and current treatment. The doctor also undertakes the functional assessment (mental health, learning, consciousness etc) described above. The claim may be approved initially on the basis of this information. After some months have elapsed, it is reviewed using the same MRA process as for Disability Benefit/ Invalidity Pension.

#### Assessment

#### - diagnosis

For a claim which starts with sickness, the claimant's own doctor initially certifies incapacity (provided he/she has been approved as a medical certifier under the Social Welfare Acts). The doctor is asked to specify an 'incapacity' which is a medical diagnosis or description of symptoms. A list of common conditions is given on the 'first certificate of incapacity' form: they include abdominal pain, fracture, cardiac disorder etc with space to specify the condition exactly. Officials in the Department of Social, Community and Family Affairs code the condition and set a referral date according to the code. If the claim continues, it is referred for medical assessment.

The condition indicated by the claimant's doctor is referred to as the 'certified cause of incapacity' (CCI). The guidance notes on the MRA system (below) state that the medical assessor 'does not dispute the existence of the CCI'; instead s/he assesses the degree of loss of function in work-related activities and its effect on the claimant's ability to work. However, the MRA form includes a 'systems review and medical examination' in which the doctor describes the person's overall state of health in terms of medical areas (mental, nervous, respiratory, circulatory, alimentary etc) and summarises the 'relevant clinical findings'.

### - standardised descriptions of physical or mental capacity

The Medical Review and Assessment (MRA) procedure is undertaken by Medical Assessors. The medical assessor records the claimant's medical and surgical history, concentrating on aspects relevant to the CCI. S/he also notes the claimant's work history and educational and vocational qualifications, and records the claimant's statement about the medical condition and its effect on 'the performance of ordinary activities of life/ work-related activity'. The assessor then provides a 'clinical description' of the effects of the claimant's condition in terms of the following functional areas:

Mental health

Learning

Consciousness

Balance

Vision

Hearing

Speech

Continence

Reaching

Lifting/carrying

Manual dexterity

Bending/ kneeling/ squatting

Sitting

Standing

Climbing stairs

Walking

In each area, the effect of the condition is indicated by the categories: normal, mild, moderate, severe, profound. The guidance notes indicate that, 'should the Functional Area seem unrelated to the CCI or any significant condition noted in the history and no gross abnormality is observable', then the area can be indicated as normal. In other words, the assessor should not explore functional limitations which are not related to the CCI. The guidance also emphasises that the assessor's view should be formed 'not on the basis of how the claimant alleges s/he is affected, nor necessarily on performance during the examination, but on your appreciation of the medical history, medical evidence furnished and relevant clinical findings..'.

The guidance advises the assessor that, should his/her opinion and that of the claimant differ as to the claimant's capacity in each Functional Area, the assessor should indicate e.g. 'Claimant's symptoms not adequately explained by objective clinical findings'. Should the assessor and the claimant concur, 'state that findings are consistent with the symptoms'.

Where a mental health problem is indicated, the assessor uses a mental health test divided into four areas:

completion of tasks

daily living

coping with pressure

interacting with other people.

These are also the four areas for the assessment of Mental Disabilities in the UK, and the guidance for assessors is very similar, in particular emphasising the importance of obtaining indirect insight into the person's mental health by getting relevant information on everyday activities and experience.

### - standardised descriptions of working life

The final part of the MRA process is the 'Work Capacity Assessment'. When the claimant has been out of work more than 6 months and there is no job open, or was never employed, the assessor considers whether s/he is capable of any of the work categories specified. These categories are combinations of job effort (light, moderate, heavy) and skill level (lesser/ semi/ skilled) - in total 9 categories from A light/skilled to I heavy/ lesser skilled. Examples are given in each category (professional, academic.. through to construction, refuse collectors).

The assessor should describe why the claimant is capable of work 'in functional terms' i.e. 'because can sit for long periods without discomfort', etc. If incapable of work, brief reference to the functional assessment suffices.

The assessor is also asked to indicate whether there is any non-functional incapacitating factor present. This refers to 'conditions which, although do not adversely affect the claimant's ability to perform any of the work-related activities, can nevertheless be deemed to be incapacitating.' These include e.g. malignant hypertension, cardiac arrhythmia, etc. It is possible that conditions which lead to general tiredness and fatigue could be recognised under this heading; it may also allow situations where a person's condition would be aggravated by work to be recognised.

### - standardised descriptions of daily life

The Mental Health Assessment (above) draws on an account of social aspects of a person's daily life.

The guidance for medical certifiers (not assessors, but own doctors issuing sick notes) state that "In cases where there is no prospect of an early return to work the certifier should consider the question of ability to work in relation to work about the house rather than to the previous occupation...

"This will apply in particular to people who look after their own home during illness and who are unlikely to return to their former occupation, in the near future." However, there is no mention of work about the house in the guidance on the Work Capacity Assessment in the MRA system.

### Institutional structures and personnel

The final decision on eligibility for benefits is taken by a clerical deciding officer, who considers the non-medical as well as medical qualifying conditions. No non-medical experts are involved in the determination of disability (referred to as 'medical eligibility').

The guidance notes for medical assessors suggest that the relationship between the MRA assessment and the view taken by the person's own doctor (who is likely to be 'approved' as a medical certifier for sickness benefits) is a sensitive one. Determination of the diagnosis/ CCI is the preserve of the person's own doctor.

Medical assessors are registered medical practitioners but are full-time employees of the Department. They have special training in Human Disability Evaluation.

### Permeability of boundaries: age, social disadvantage

Invalidity pension can only be awarded to people under the old age pension age, but it continues in payment after pension age. Invalidity pension rises for those aged 65-80 and again for those aged 80+.

#### **ITALY**

#### **Provisions**

The discussion here concentrates on the *Assegno ordinario di invalidita* (Ordinary Invalidity Grant), which is a contributory allowance payable to people who have lost 67%+ of their capacity to work in their previous occupation. There are also non-contributory income support measures, notably the *Pensione di inabilita*, which is payable to those assessed as having lost 100% of their work capacity in <u>any</u> occupation, and the *Assegno mensile*, a monthly grant for those whose working capacity is reduced by at least 74%. Assessments for these latter benefits, along with grants for people needing care and accompaniment, are done by Medical Panels of the National Health Service.

#### Decision to be made

Whether the worker has lost 67%+ of his or her 'capacity to work' (*capacita di lavoro*). This concept is distinguished from 'capacity to gain' (*capacita di guadagno*). A court ruling in the early 1970s established that the assessment of 'capacity to gain' must take account of local labour market conditions. Thus if the labour market was depressed, a person's capacity to gain was reduced.

A study in 1980 concluded that this approach had contributed to a big increase in the number of awards, and argued that the invalidity pension was being used as a form of early retirement. Reforms in the 1980s changed the criterion from 'capacity to gain' to 'capacity to work'

There is no partial incapacity; however it is possible to combine AOI with some income from work

#### Process of becoming unable to work; employer's responsibilities; rehabilitation

There is no statutory sickness benefit for blue-collar workers. The law requires that white collar workers benefit from wage continuation for 3 months in case of sickness.

INPS (National Institute for Social Protection) can finance medical rehabilitation.

### Assessment

#### - diagnosis

Initially a medical practitioner chosen by the patient fills in an INPS questionnaire, stating the diagnosis.

## - impairment

Medical practitioners employed by INPS carry out a medical assessment and make a medical legal report. This assessment involves a complete examination of the functioning of the main physical systems. The diagnosis of the patient's own doctor is reviewed and other health conditions may be noted by INPS practitioners. Protocols are used that give close attention to diagnosis and associated impairments in particular areas, e.g. cardiology, neoplasm. However, the assessment cannot be based solely on these protocols (by contrast with assessment in the industrial injuries and occupational disease scheme, where impairment tables have a statutory basis and are heavily used). The law indicates that there must be a personal evaluation of residual working capacity for AOI, which precludes total reliance on standardised tables.

### - job abilities or requirements specific to the person

This part of the assessment is based on the work usually and prevalently done by the claimant. The job done by the claimant is interrogated using a detailed questionnaire which highlights features of the work: heaviness, work position (sitting, standing etc), environment (humidity, temperature, use of stairs and ladders), use of machines and particular instruments.

Some of the protocols developed in INPS link diagnosis to functional limitations and thence to particular difficulties in performing certain types of work (as well as other effects on daily life). Since the law refers explicitly to a person's previous job (or, more precisely, to the type of job a person has been oriented to in the past), the identified impairments must be set against the concrete requirements of the previous job.

## Institutional structures and personnel

The specialised medical staff employed by INPS have a central role. Their decisions are binding on INPS. The specialised content of medical insurance law, as applied by the INPS medical practitioners, serves to deflect conflict between the person's own doctor and the INPS doctors. A claimant seeking to challenge an INPS ruling will generally seek support from another expert, not from his or her own doctor.

The law leaves a lot of discretion to the medical assessor. However, INPS itself has to some extent filled the discretionary space by developing protocols which guide the doctors in INPS section offices. These protocols are an internal administrative instrument. Appeals are to the Labour Court are frequent. The judge appoints a specialist to evaluate the case.

# Permeability of boundaries: age, social disadvantage.

Usually, invalidity benefits cease at pension age (currently 65 for men, 60 for women). Exceptions are when the recipient is working or when contributions are inadequate for an old age pension (5 years' contributions are needed for invalidity benefits; 15 for old age pension).

#### **NETHERLANDS**

#### **Provisions:**

The most important income support provision for people with reduced ability to work due to disability is *Wet op de Arbeidsongeschiktheidsverzekering* (WAO). While technically a contributory benefit, the contribution requirements are minimal. There is a separate provision for young people who have never worked (*Wajong*). Partial awards of WAO can be combined with partial receipt of unemployment benefit. General social assistance may also be claimed to top up WAO but no other test of inability to work is involved.

#### Decision to be made

Contributory benefits are provided under WAO for people who, as a result of sickness or impairment, cannot earn through work what not-disabled people, with comparable education and work experience, usually earn (Netherlands report, p.7). Partial pensions are payable: the minimum percentage loss of earnings capacity is 15%, and losses are rated in 10% bands above this level (15-25, 25-35 etc) up to the two highest bands which are 65-80% and 80%+.

## Process of becoming unable to work; employer's responsibilities; rehabilitation

For an employed person, an application for WAO benefits generally begins with a period of sickness. Reforms in the 1990s sought to place much of the financial responsibility for sickness on employers, in order to enhance incentives for reintegration. Employers face a financial penalty if their workers become disabled in the form of experience-rating of insurance contributions.

After 13 weeks of sickness, the employer must develop a rehabilitation plan. Sick employees are protected against dismissal for up to two years; permission to dismiss earlier must be sought from the regional employment office or district court and requires proof that it will be impossible to accommodate the person within the company (Høgelund and Veerman, 2000, p.4).

# Assessment

### - diagnosis

The insurance physician does not investigate the medical diagnosis, which is taken from the records provided by the person's treating physician.

Once an application for WAO benefits is made, the claimant's earning capacity is assessed in two stages: (1) by developing the claimant's 'capacity profile' and (2) by examining the effect of the limitations in capacity on potential earnings. Step (1), the capacity profile, is developed by an insurance physician, step (2) by a labour expert. Both are employees of the social insurance administration.

### - standardised descriptions of physical or mental capacity

The main procedure in Step 1 is an oral interview where the physician records the claimant's account of his or her health problems and ability to undertake different activities (limitations in functioning). There is debate among physicians about how the 'causality principle' (that limitations must be the result of sickness or impairment) should be applied, with differences of emphasis on the loss itself versus the causal link (Netherlands report, p.10).

In practice, some 35-40% of claimants are assessed as having 'no lasting capacities left' at step 1 (Netherlands report, p.8). Grounds for this decision may be that the claimant is hospitalised, in residential care or bedridden, is not able to cope for himself and depends on others for his daily tasks, or is unable to cope mentally and is thereby hindered in social relationships. In a recent study, 80% of those found to have no lasting capacity belonged to the latter group of those unable to cope mentally (Netherlands report, p.13).

Physicians use a standardised approach for measuring a claimant's functional ability to perform work, which defines 28 different types of task required in different occupations, including:

sitting standing walking climbing stairs

climbing kneeling, crawling, squatting

bending

short cyclic bending and turning

liftina

pushing and pulling

carrying use of neck reaching

working above the head

hand-finger dexterity

environmental aspects (reactions to heat, dryness etc)

contact with skin (e.g. allergies)

vibration

use of special tools on the body (e.g. masks)

personal risk (e.g. accident proneness)

psychological criteria (working with others, tempo, stress etc).

For most tasks, the assessor rates the claimant as 'normal' or 'not normal'; in some cases, measures of duration of ability to perform the task are recorded.

#### - standardised descriptions of working life

The process then moves to step (2): assessing the degree of loss of earning capacity, which is done by a labour expert. This expert also interviews the claimant and obtains information on his or her education, skills and experience. To determine the remaining earning capacity, the expert identifies jobs that the person can still do. These jobs do not have to be available (to have vacancies). They must be 'generally acceptable' but do not have to be as high in status as would fit the claimant's educational level or previous work experience (Netherlands report, p.10).

The main formal instrument used by the expert to identify possible jobs is the Function Information System (FIS). The operation of this computerised system is currently being reformed, but as at June 2001 it worked as follows. The system contains descriptions of thousands of jobs existing in the Dutch labour market, recording:

- 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..)
- job description (purpose, content, tasks)
- the functional capacity demands of the job expressed in terms of scores on the 28-point capacity standard used by the physician at step (1).

The expert uses this computer database to identify at least three jobs the claimant could do. If three jobs cannot be identified, the claimant is assessed as fully disabled. The three jobs with the highest income level are selected and the median income level indicates the claimant's residual earning capacity. This is compared with the earning capacity of a comparable person with no sickness or impairment: generally the claimant's wage before the onset of illness is used to indicate this.

- job abilities or requirements specific to the person

The degree of loss a person has suffered is assessed relative to the earnings of a similar person without the incapacitating condition: in practice, the previous earnings of the person provide the benchmark.

#### Institutional structures and personnel

Insurance physicians have a major role: note the number of claims which stop at step 1. Lack of staff and time pressure in making decisions appear to be important issues.

At the end of a period of widespread institutional reforms, the different social security agencies involved in disability determination are to be integrated into a single national agency, which is seen as facilitating fairness and consistency in decision-making.

The government has sought to improve the uniformity and objectivity of decisions by promulgating legal standards in the form of statutory instruments (Assessment Regulations).

### Permeability of boundaries: age, social disadvantage

It is evident that the Dutch authorities find the boundaries of WAO to be too permeable. There have been a number of efforts to reduce the number of disability claims in the Netherlands, most notably with the Act on Reducing Claims (TBA) in 1993 (Netherlands report, p.12). This Act widened the range of jobs that might be considered from those thought 'suitable' to any 'generally acceptable' jobs. It also sought to reduce the discretion of the insurance physicians, particularly by emphasising the causality principle (that functional limitations should be the direct and objectively medically assessable result of sickness or impairment). However, with a high proportion of cases decided at Step 1 on the basis of mental health problems, this principle is difficult to apply.

Policies have also been adopted to promote return to work among WAO recipients. People assessed as partially disabled may work, although earnings in excess of those implied by their assessment of earnings loss will tend to lead to reassessment. About half those assessed as partially incapacitated are working (Beljaars and Prinz, 2000, p.5). A partially-disabled person may also claim partial unemployment benefit if he/she is not able to find a job suited to his or her remaining capacity. It is possible that the Dutch system compensates for loss of earning capacity due to poor health in situations where other states would regard a person's capacity as remaining adequate (because they do not look at loss but at current capacity relative to benchmarks of ability to work). Compensation for loss, and the range of degrees of loss (starting from 15%, a low level for general disability benefits in comparative perspective) may reflect the integration into the general disability system of the system for compensating for industrial accidents and occupational diseases.

WAO is contributory but does not require a minimum period of affiliation. However, it does require a person to be working before the onset of disability, and those too young to have worked before the development of a disability are subject to a different scheme (Wajong). Older people (such as housewives) who were not working before the onset of illness or impairment may not be eligible for WAO.

WAO ceases when person reaches old age pension age of 65 for both men and women. There is no early retirement pension in the old age pension system.

A wide-ranging discussion of the reasons for higher numbers of recipients in the Dutch system than other European systems can be found in Beljaars and Prins, 2000.

#### **NORWAY**

# **Provisions**

The main long-term income provision for people unable to work due to illness, injury or defect, is *uførepensjon*. This is an early retirement pension for people deemed (partially or totally) incapable to work.

For people without past earnings above a certain minimum level, there is a flat-rate basic pension (*grunnpensjon*). In addition they will receive a special supplement (*særtillegg*), to guarantee a certain income (*minstepensjon*). For persons who have past earnings above the minimum level an earnings-related supplementary pension (*tilleggspensjon*) is provided. These provisions are part of the National Insurance Scheme (*folketrygden*). All residents in Norway are members of this scheme. Full *minstepensjon* is provided to old age pensioners who have been members for 40 years, for others it is reduced according to the number of years of membership (minimum 3 years). For people born with impairments or who became disabled in young age special rules of benefit calculation apply.

In addition to sickness benefit (*sykepenger*) (paid maximum one year), rehabilitation benefits (medical and vocational) are payable to people with long-term illnesses or disabilities. Medical rehabilitation allowance (*rehabiliteringspenger*) is paid for maximum one year, while vocational rehabilitation allowance (*attføringspenger*) can be paid for several years.

#### Decisions to be made

According to the National Insurance Act persons between the age of 18 and 67 can be granted an *uførepensjon* if their work capacity (understood as earning capacity) has been permanently reduced at least 50 % because of illness, injury or defect. These general eligibility criteria are similar to those for the rehabilitation provisions. In the case of *uførepensjon* decisions about claims are made by the National Insurance Administration (*Trygdeetaten*), on the basis of assessments made by external expertise, especially medical doctors and staff in the Employment Service (*Aetaten*).

## Process of becoming unable to work; employer's responsibilities, rehabilitation

According to the National Insurance Act (Section 12-5) a person does not qualify for *uførepensjon* unless 'appropriate treatment and vocational rehabilitation' has been tried in order to improve his/her earning or work capacity. As a matter of routine the National Insurance Administration is required to judge whether there is any scope for vocational rehabilitation measures, in order to assist the person in regaining or improving his/her work/earning capacity. As part of this responsibility, staff are expected to refer claimants who may benefit from participation in vocational rehabilitation measures to the Employment Service (*arbeidsmarkedsetaten*). In certain cases of fatal or compound impairment (according to a standardised list of diagnoses) the National Insurance Administration will itself decide that further testing of work capacity and employment prospect is not necessary.

The Employment Service assesses whether participation in vocational rehabilitation measures is 'necessary and appropriate' (ibid. Section 11-6). These offices may also refer the person to regional centres for employment quidance (arbeidsrådgivningskontorer) for more detailed vocational assessment. The Employment Service makes the decisions about claims for vocational rehabilitation allowance and the initiation of practical measures. When deciding whether vocational rehabilitation measures are necessary and appropriate the Employment Service is supposed to take into account the person's age, general abilities, education, work experience, prospects for employment locally as well as elsewhere where it is reasonable that the person seeks work (ibid. Section 11-5). The law do not state any explicit limitation about what type or kind of work the person is expected to take up, apart from the general requirement that this work should be 'suitable' (høvelig) for the person (Section 11-6. If the Employment Service comes to the conclusion that vocational rehabilitation is not necessary and appropriate the person will be referred back to the National Insurance office, for a final decision about the claim for disability pension.

The most common 'route' towards claiming *uførepensjon* goes through one or several periods of sickness absence and participation in rehabilitation measures.

- After 8 weeks of sickness absence the person's own doctor is required to produce a detailed certificate (*sykemelding II-skjema*). The doctor is supposed to inform the National Insurance Administration about on-going treatment, plans for further treatment and possible rehabilitation measures. The doctor uses the same form as in cases of claims for rehabilitation allowances and *uførepensjon*.

- The employer pays sickness benefit in the first two weeks of absence, after that National Insurance Scheme takes over the responsibility for the payments. But during the whole sickness period the employer has a duty to consider and implement practical arrangements necessary in order to promote the patient's return to work. Sick workers can for instance re-enter work gradually (*graderte sykepenger*) or through *aktiv sykemelding* (active sick-leave). These arrangements are used for the purposes of securing that the employee does not lose contact with the workplace and of testing his/her capacity to perform regular work. The arrangements are voluntarily, but frequently used and encouraged by both the National Insurance Administration and doctors. Formally the employer has also a legal obligation to provide a written statement to the National Insurance Administration about what arrangements that can be made in the workplace to facilitate the patient's return to work (National Insurance Act, Section 25-2) but this rule has little or no practical significance.

According to the Work Environment Act (*Arbeidsmiljøloven*) the employer has a duty to make the working place accessible and provide alternative job options or technical adjustments (Section 13). Formally employee on sick leave can only be dismissed if such measures have been implemented without success. Yet employers are only obligated to implement such measures 'as far as possible'. In practice many employers fail or neglect to make any such arrangements. The Labour Inspectorate (*Arbeidstilsynet*) (and eventually the courts) are likely to accept this if the employer can prove that to implement such measures would jeopardize the economic viability of the company or make it necessary to dismiss other personnel.

The National Insurance Administration is supposed to provide information and guidance to employers about financial and practical support to adopt technical equipments or adjusted working arrangements. In practice this has only had a limited impact. The government has recently decided that reassignments, changes in jobs or the work environment and other rehabilitation measures in the workplace are to be used more actively to promote recruitment of for disabled workers and prevent exclusion from employment both in the private and public sectors of the economy.

#### Assessment

# - diagnosis/ impairment

doctor is required to certify the medical condition, i.e. the relevant medical diagnosis/diagnoses, and assess the consequences of this/these. Diagnoses must be acceptable by international standards and the ICPC, ICD-9 or ICD-10 are used for coding purposes. The doctor is supposed to judge whether the medical condition restricts the person's 'functional ability' (*funksjonsevne*), that is, leads to impairment.

No standardised (listed) descriptions or categories have been used so far. The government is currently considering to adopt more standardised descriptions of the type and form of impairments (*funksjonsvurdering*, i.e. 'functional assessment').

### - job abilities or requirements specific to the person

The doctor assesses what consequences the impairment has for the person's work capacity (*arbeidsevne*). The doctor is expected to consider both the patient's prospects for a return to his/her previous work and possibilities to take up any other type of work. As part of this, the doctor is supposed to judge what kind of work-related activities or operations that the patient *cannot* perform. The doctor is also to provide prognoses, i.e. estimate the expected durations of the medical condition, the impairment and the diminished work capacity. The National Insurance Act demands that there should be clear causal links between the medical condition, the impairment and the diminished work capacity, and that the impairment should be the main cause for reduced work/earning capacity (Section 12-6). According to this the doctor is required to assess how great impact the impairment has on the diminished work capacity. The doctor is also asked to give his/her opinion whether any vocational rehabilitation measures ought to be initiated.

### - personal and social circumstances specific to the person

Uførepensjon is payable according to varying levels of diminished work capacity (50, 60, 70, 80, 90 or 100% reduction) (Section 12-11). When the National Insurance Administration decide to what degree the person's earning capacity has been reduced it is supposed to consider the person's age, general abilities, education, work experience, prospects for employment locally as well as elsewhere where it is reasonable that the person seeks work (Section 12-7).

### Institutional structures and personnel

The person's own doctor usually does the main medical assessment. Only if deemed necessary by the National Insurance Administration will special in-service doctors (rådgivende leger) be consulted in order to review the quality of the information and assessment in the medical certificate produced by the person's own doctor and in rare cases, call the claimant for an interview.

In Norway vocational rehabilitation is seen as an integral and important part of the remit of both the National Insurance Administration and the Employment Service. Inter-agency collaboration and co-ordination measures between these two are institutionalised, most commonly through regular meetings (e.g. <code>basismøter</code>). Similarly these administrations are supposed to co-operate in order to secure early intervention, prevent exclusion from gainful employment and/or promote return to work. The National Insurance Administration is responsible for the 'clinical' period and the contact with clinical actors (general practitioners, medical specialists, other therapeutic personnel), that is, the period where the patient undergoes medical examinations and treatment. The employment administration is responsible for the period in which the claimant takes part in vocational rehabilitation measures (e.g. re-training or re-qualification measures, job-training in public/private sector; sheltered or open labour market employment).

### Permeability of boundaries: age, social disadvantage

The government has in recent years tried to limit the scope for taking into consideration personal and social circumstances, e.g., by emphasising more strongly the possibilities of geographical mobility in order to improve prospects for finding alternative employment. This tightening of both rules and administrative practice also means that the scope for individual preferences and motivations has been somewhat diminished. When the Employment Service is deciding whether vocational rehabilitation measures are 'necessary and appropriate' it is supposed to take into account the person's age, general abilities, education, work experience, prospects for employment locally as well as elsewhere where it is reasonable that the person seeks work Similarly, when the National Insurance Administration decides to what degree a person's earning capacity has been reduced it is to consider his/her age, general abilities, education, work experience, prospects for employment locally as well as elsewhere where it is reasonable that the person seeks work. In both cases this suggests that an overall assessment of the 'whole' life situation of the person is to be made. There is little systematic knowledge about to what extent and exactly how staff in the two services exercise these discretionary judgements, e.g. whether all the factors mentioned in the law are given the same weight.

Rehabilitation provisions and *uførepensjon* stop at the age of 67 for both men and women. At this age all residents of Norway are eligible for old age pension. Persons older than 62 years can receive *avtalefestet pensjon (ATP)* up to the age of 67 years. This early retirement pension is basically financed through collective agreements between unions and employers' organisations (plus some public contributions). It is mainly paid to persons who have been employed continuously for a long period. High age (more than 55) can influence the decision about granting a disability pension, if the person is seen difficult to reassign to alternative employment. But he or she must still fulfil the medical criteria discussed above. Another 'route' into disability pension exists for persons experiencing long-term unemployment or persons who are socially disadvantaged. But again, they must fulfil the stated medical criteria, which require that their earnings capacity is reduced because of illness, injury or defect, and not only through general life difficulties or lack of income.

#### **PORTUGAL**

#### **Provisions**

Portugal has a contributory invalidity pension (*pensão de invalidez*) and a non-contributory 'social invalidity pension' (*pensão social de invalidez*). Both are now governed by a single law (17/2000), but this law is not yet fully in force. There is also a general social assistance provision, the *rendimento minimo garantido*, which was introduced in 1996-7.

#### Decision to be made

The disability criterion for entitlement to invalidity pension is that a person cannot earn more than one-third of the wage he or she previously earned, in any occupation. There are no partial awards and recipients cannot retain any entitlement to invalidity pension if they work.

## Process of becoming unable to work; employer's responsibilities; rehabilitation

No information available.

#### Assessment

- diagnosis
- impairment

The 'reporting doctor' always conducts an examination and provides a diagnosis. The Service for Verification of Incapacity may also obtain other medical reports.

The recommendation of the reporting doctor is based on the National List of Incapacity (Decree-Law 341/93). This list is organised in chapters which resemble those in the AMA Guides (although the chapters are not identical), listed in the Annex. Thus the list is organised around diagnostic categories such as neurology, dermatology, endocrine system etc. There are two chapters relating to disfiguring afflictions and injuries to the face.

As noted in the main report (chapter 3), impairment rubrics may have different 'levels of measurement' in different sections, and this is true of the Portuguese rubric. The chapter on the musculo-skeletal system (*Aparelho locomotor*) is organised to allow the percentage of disability to be derived directly from the precise measurement of restrictions of movement or other limitations of specific body parts, while some other chapters have no percentages given. The chapter on cancers and tumours directs the doctor to examine the effect of the cancer in terms of anatomical alterations and effects on functioning described in other chapters.

To complete the assessment form, the doctor must indicate the chapter and section relating to the diagnosis and put down the 'coefficient of incapacity' as indicated in the table (although the table may indicate a range of values). This coefficient can be adjusted; the doctor has to explain the adjustment. The form then provides columns for calculating the 'global coefficient of incapacity' from the individual coefficients for each impairment.

## - job abilities or requirements specific to the person

The Guide does allow for the determination of the degree of invalidity to be influenced by the work that the person normally does, e.g. whether the job is intellectual or manual. Some specific occupations are indicated as limited by specific impairments, e.g. performers (actors etc) and those who deal with the public are indicated as more affected by disfigurement.

### - personal and social circumstances specific to the person

While the structure of the Guide might suggest that its application is rigid and predictable, the wording of a number of sections indicates that the doctor retains a high level of discretion in determining exactly what the impact of an impairment is on a particular person (see also below).

#### Institutional structures and personnel

The existence of a single national list of impairments which is referred to in a wide range of Portuguese provisions might suggest that the institutional affiliation of the user of the list would not be of central importance, and that determinations made using the List would be applicable in a wide range of contexts. However, some parts of the List clearly envisage particular contexts: for example, there are specific notes relating to impairments resulting from industrial injuries and occupational diseases at various points in the List.

The List constitutes binding law and must be followed e.g. by judges in the appeal process. However, it leaves plenty of scope for interpretation.

## Permeability of boundaries: age, social disadvantage.

The preamble to the 1993 National List (*Tabela nacional de incapacidades*) describes the history of the list, which originated with the adoption in 1932 of the Lucien Mayet table developed in France and used for industrial injuries determinations. The preamble states that the List has been revised in the light of developments in medicine and changes in the technology of work. It also notes the rigid character of the earlier tables. The new table is intended to allow a more flexible approach.

#### **SPAIN**

#### **Provisions**

There are two main forms of income support for disabled people: contributory incapacity pensions and non-contributory invalidity benefits. The contributory scheme has been in existence for many years (most elements of the current system were in place by 1966; the previous system (SOVI) was abolished from 1 Jan 1967 although some transitional elements remain in place). The non-contributory benefit was envisaged by the general law on the social integration of the disabled (LISMI: Ley 13/1982, 7 April, Ley de integracion social de los minusválidos). The law governing both benefits is now consolidated in the General Law on Social Security (Ley General de la Seguridad Social, LGSS). However, the definitions of disability used in the two schemes differ considerably, and the institutions involved in their administration are also quite separate.

#### Decision to be made

In the contributory mode, permanent incapacity (*incapacidad*) is the situation of a worker who, having had appropriate medical treatment, presents or displays serious anatomical or functional limitations, which are susceptible to objective determination and foreseeably permanent, which diminish or annul his capacity to work (*capacidad laboral*). (Art 136(1) LGSS).

In the non-contributory mode, invalidity (*invalidez*) is the result of impairments (*deficiencias*), which are permanent for the foreseeable future, which may be physical or mental, congenital or not congenital, which annul or modify the physical, mental or sensory capacity of the person who suffers from them. (Art 136(2) LGSS)

Older versions of the social security laws use the term 'invalidez' relating to contributory benefits, but 'incapacidade' is now preferred.

It can be seen that the two definitions differ, particularly in that the definition for the contributory pension refers specifically to capacity to work, while the non-contributory definition does not. The definition for the contributory pension also refers to <u>reduction</u> of capacity, whereas the other definition appears to be more oriented towards impairments which may be manifest from birth or childhood.

There are four rates of Social Security incapacity pension: *parcial, total, absoluta* and *gran invalidez*, defined as follows:

- *Parcial*: permanent partial incapacity for habitual occupation. Work capacity reduced by 33%+ due to illness or injury.
- *Total*: permanent total incapacity for habitual occupation. In addition, there is the possibility of 'qualified' total incapacity, whereby it is assumed that a worker will not be able to obtain a different job than the habitual one due to age or other circumstances. A worker aged over 55 is automatically 'qualified'.
- Absoluta: permanent total incapacity for work of any type
- Gran invalidez: total incapacity for work and, in addition, the recipient is unable to undertake activities of daily life (getting dressed, moving, eating etc) without the aid of another person. (Art 137 LGSS)

The non-contributory benefit is payable if a person is assessed as having more than 65% disability according to the rubric provided by Real Decreto 1971/1999. Additional amounts for care and mobility needs can be provided (as for the insurance-based category of *gran invalidez*): they are subject to an additional assessment which is discussed in Appendix 3.

# Process of becoming unable to work; employer's responsibilities; rehabilitation

Benefits are payable for 12 months with possibility of extension for a further 6 months where there is deemed to be a chance of the beneficiary once again being fit for work. Unfitness for work certified by doctors of the Health Service.

The process of assessment for permanent incapacity can be initiated by the Provincial Directorate of INSS when the period of temporary incapacity expires, or on the request of the Inspectorate of Work, or the Health Service (INSALUD) or the persons themselves or their representatives.

#### **Contributory Incapacity Pensions**

It is the task of INSS to regulate the bodies which determine the state of permanent incapacity for the purpose of the contributory social security benefits (Art 143(1) LGSS). The medical part of the determination is done by the *Equipos de Valoración de Incapacidades* (EVI) which are organised under the provincial offices of INSS. However, as at 2000, EVIs had not been established in provincial offices in Catalonia and Euskadi (the Basque country) (Footnote 433. p.204 LGSS).

#### Assessment:

Doctors at the EVI produce an opinion and proposed decision called the *Informe Medico de Síntesis* (IMS). The final award of benefit is made by the Provincial Administration on the basis of this recommendation and the non-medical factors.

# - diagnosis

The EVI obtains, as available, the clinical file from the Health Service, and /or any medical report from the INSS work inspection service, and other medical data. This information is summarised in the IMS. (Details - Arts 8-10 of Order 18 Jan 1996 (Decree 1300/1995)).

In order to ensure that the evaluation is as objective as possible, the assessment of the person's limitations or impairments is based on the doctor's knowledge of the nature of the illness or injury. In the eyes of Jardon-Dato, an EVI co-ordinator in the central office of INSS, it would be desirable to develop a listing of causes of incapacity which can be codified. Each of the causes or processes would have a rubric setting out the rules and protocols for its diagnosis and grading, the impairments which can result, and methods for evaluating the impairments (Jardon-Dato (2000)).

## - impairment

The IMS assesses the 'residual functional capacity' of the worker and sets this against the demands/ requirements of the job the worker was doing and/or general requirements in the labour market. In so far as there are instruments for doing this, they are more oriented towards impairment than towards 'standardised descriptions of physical or mental capacity' as that term has been used in this paper.

## - job abilities or requirements specific to the person

The application for the assessment of permanent disability indicates the date of stopping work and its cause, the habitual occupation of the worker, his or her professional category and a description of the actual work that was done.

# - personal and social circumstances specific to the person

Jardon-Dato emphasises that the attitude or self-assessment of the worker is not, and cannot be, taken into account in the evaluation, which must rest on an objective comparison of the functional limitations with the demands of work.

## Non-contributory pension of disability

#### Assessment

For the purpose of this benefit, a person's degree of disability (grado de minusvalía) is assessed by offices for evaluation and orientation (equipos de valoración y orientación) which are 'under the direction of the Institute of Migration and Social Services (IMSERSO) or the corresponding organs of the Autonomous Communities, to which these functions have been transferred' (preamble to Real Decreto 1971/1999). In practice centres for the disabled established under the social services directorates of the Autonomous Communities do the assessment.

The Guide *Valoración de las situaciones de minusvalía* (VM), which was given legal status by Real Decreto 1971/1999, is intended to guide the work of the centres. Prior to the promulgation of the Real Decreto, the assessment envisaged for non-contributory benefits was meant to follow a barema contained in an Order from the Ministry of Labour and Social Security in 1984 (8 March 1984). However, the lower legal status of this Order and variations in practices adopted by the autonomous communities led to the promulgation of a more authoritative statement of how disability should be assessed. Article 1 of Real Decreto 1971/1999 notes the need for a system of grading disability which ensures some consistency in assessment across the territory of Spain.

The Guide is published by IMSERSO and updated in response to, for example, changes to the AMA Guides (see below).

#### - diagnosis

The evaluation of disability is based on the severity of the consequences of an illness, not on the diagnosis of an illness (ch 1, *Normas Generales* of the Guide VM, point 2). However, the analysis of impairment is structured around diagnostic headings.

## - impairment

The Introduction to the Guide refers to the WHO definition of disability, which is 'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being', and at several points in the opening chapter on General Norms, it is stated that disability should be understood by reference to the effect of an impairment on the performance of activities of daily life (ADLs). However, the ADLs referred to do not correspond to the heading of 'standardised descriptions of daily life'used in these summaries: they include elements of standardised descriptions of physical or mental capacity (see below).

In its details the Guide utilises much of the content of the AMA Guides to Permanent Impairment (see Appendix). As noted in the Introduction and discussed by Matheson et al (2000), the AMA Guides develop the idea of impairment and its effects at a variety of levels,

depending on the nature of the impairment being assessed. This is also true of the Spanish Guide. The Guide has the characteristic 'disaggregative' structure of impairment rubrics, whereby degrees of disability are determined for parts of the body and then combined into an overall class expressed in percentage terms. Within some chapters, rubrics are provided for calculating the overall level of disability (*discapacidad global persona*) from specific disabilities. For example, a communication disability of 60-84% gives an overall disability rating of 36-50%. In assessing the musculo-skeletal system, the tables show how degrees of loss (amputation or lack of movement) e.g. in a finger translate to degrees of loss in the hand overall; these in turn translate into degrees of loss in the 'upper extremities' and these translate into percentages of disability. E.g. 100% loss of finger = 10% loss of hand = 9% loss in upper extremities = 4% percentage of disability.

However, not all the chapters take the same approach. Some chapters have schemes for determining 'classes' of disability. Each class may have four or five components, including:

- diagnosis ('the person has such-and-such a condition')
- treatment (higher classes of disability are connected with more debilitating treatments)
- technical medical measures of the condition
- the 'grade' of disability, referring to the effect on ADLs.

In the chapter on mental illness, the 'class' 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. It is also noted that drug addiction should not be treated as a condition in itself: instead, a predisposition to addiction and/or pathologies associated with the addiction may provide the basis for a classification.

- standardised descriptions of physical or mental capacity

While the Guide has a pronounced 'impairment' orientation, statements about performance can be found throughout, particularly in areas where technical medical measures are not available. For example, the chapter on language includes statements about whether the person can be understood by family, friends, strangers etc. (The chapters on vision and hearing, by contrast, rely on technical measures.) Note also that the AMA ADLs (see below) include some elements which come under this heading.

- standardised descriptions of working life

Brief descriptions can be found in the Mental Illness chapter:

- standardised descriptions of daily life

The introduction to the Guide refers to the AMA ADLs, as follows:

- 1. Activities of self-care (dressing, eating, avoiding risks, cleanliness and personal hygiene)
  - 2. Other activities of daily life:
  - 2.1 Communication
  - 2.2 Physical activity
    - 2.2.1 Intrinsic [moving oneself] (to get up, to dress, to sit down)

- 2.2.2 Functional [manipulating things] (to carry, to lift, to push)
- 2.3 Sensory functions (hearing, sight..)
- 2.4 Manual functions (grabbing, pressing..)
- 2.5 Transport (this refers to capacity to utilise [various] means of transport)
- 2.6 Sexual functioning
- 2.7 Sleep
- 2.8 Social activities and leisure
- personal and social circumstances specific to the person

If a person has a degree of disability of 25% or more on the medical assessment (as described above, including the elements of effect on ADLs), then 'social' factors may be taken into account, adding a maximum of 15% to the medical percentage.

The factors outlined in Real Decreto 1971/1999 include:

- Family factors: amount of family support, family relationships, functioning of the family
- Economic factors: these are rated by taking the total family income, deducting extra costs related to the person's disability, dividing the income by the number of family members and comparing it to the minimum wage.
- Work factors
- Cultural factors

However, the approach to social factors outlined in the Real Decreto is developed differently in the different regions (autonomous communities), particularly in the light of the different 'orientation' options (sheltered workshops, rehabilitation, education) available to the centre conducting the assessment.

### Institutional structures and personnel

There is an emphasis on a multi-disciplinary approach in the constitution of evaluation centres for implementing the Real Decreto, which provides that the assessment team must include a psychologist and a social worker as well as a doctor (Art 8(1)). The committees of EVIs are dominated by doctors and administrative officials, although there is provision for rehabilitation experts and/or occupational health experts to be brought in.

## Permeability of boundaries: age, social disadvantage

The old age pension age is 65, although those with transitional rights from SOVI may retire at 60. Early retirement provisions exist for those working in arduous, toxic, dangerous or unhealthy environments.

### **SWEDEN**

### **Provisions**

The main long-term income support provision for people unable to work due to illness or injury is the early retirement or 'before time' pension, the *förtidspension*. For people without a work/ contributions history, this is a flat-rate pension; for those who have contributed to social insurance, it is earnings-related.

In addition to sickness benefit (usually paid for a maximum of one year), rehabilitation benefits can be paid for several years.

### Decision to be made

According to the Social Security Act, people may receive the *förtidspension* if their work capacity is reduced because of accident, disease or for other medical reasons. The medical factor can be physical or mental illness, the consequences of such an illness, or that the person was born with a handicap. There are four levels of work capacity reduction (.25-<.5; .5-<.75; .75-<.875; .875+ ('totally or almost totally')). These reductions are not framed in terms of reduced earnings potential; implicitly a person is assessed against the capacity of an average worker, rather than with reference to the capacity he or she previously displayed.

There is no explicit reference to whether the test is capacity to work in the general labour market or in one's previous occupation, but flexibility (transfer to another occupation) is implicit in the step-by-step process described below.

## Process of becoming unable to work; employer's responsibilities; rehabilitation

Sickness benefits become the responsibility of the social security system after an initial 13 days of wage continuation (payable by the employer).

After 28 days the employer, the sick person and the social insurance office should agree on a rehabilitation plan. The plan may simply indicate that the person is expected to resume his or her job on recovery; however it may also look at possible rehabilitation measures and/or job reassignment. Under the Employment Protection Act (LAS, 1974/1982), sickness is not an acceptable reason for an employer to dismiss a worker, unless it can be shown that the employee cannot perform important work tasks and that all possible steps by way of reassignment, work environment improvement and rehabilitation have been undertaken.

Where there is no employer, the rehabilitation plan is the responsibility of the Social Insurance Office (*Försäkringskassan*). In discharging this responsibility they may work closely with the rehabilitation services (*AF-rehabilitering*) which are part of the labour market services system (under the National Labour Market Board, AMS). Referrals to *AF-rehabilitering* often occur when it is out of the question that the person return to his earlier job and when further information is needed concerning the individual's preferences, talent and work capacity. The staff of AF-rehabilitering often consist of occupational therapists, psychologists, social workers and employment officers.

In principle, a person can also be found to be insufficiently incapacitated to require rehabilitation services, in which case responsibility for his or her support will pass to the unemployment insurance funds or to social assistance.

There is no formal time limit for receipt of sickness benefits, but policy is to ensure that 'passive' sick list periods do not exceed one year. Compared with other countries, processes for investigating rehabilitation and checking on the prospects for a return to work begin relatively early in Sweden.

Rehabilitation options, involving changes of job or employer, are explored in a 'step-by-step' process.

### Assessment

- diagnosis
- impairment/ descriptions of physical or mental capacity

A medical certificate from the person's own doctor is required after 7 days. After 28 days of sickness more extensive medical certification is required. This indicates:

- the diagnosis (if available), as well as the symptoms
- the medical examination undertaken
- functional and work capacity.

There are no formal or legal listings used to describe functional and work capacity. Assessment is made according to the circumstances in each case.

The certificate is completed by the person's own doctor and reviewed by a doctor engaged by the Social Insurance Office.

Shortcuts - special treatment due to particular diagnoses/ conditions: for some diagnoses, the initial medical certificate will suffice to indicate lack of work capacity and unsuitability of rehabilitation. Sickness insurance is payable at a higher rate than long-term sick benefit/ förtidspension so there is no incentive to move quickly onto the latter benefits.

- job abilities or requirements specific to the person

At step 5 in the step-by-step process, the person's ability to take on another normally available job without vocational rehabilitation is considered. There are no prescribed procedures for how to assess if the sick person can take on a job normally available in the labour market or to survey which jobs are available at a certain point of time. This assessment is usually done by the official at *Försäkringskassan*. This may involve a dialogue with the advisory medical doctor employed by the social insurance institution, in cases where medical diagnosis and/or impairment consequences are difficult to interpret. It is not required that labour market authorities be consulted, although this often happens.

## - personal and social circumstances specific to the person

The final step of the step-by-step process is reached when it is thought that there is no prospect of the person taking a normally-available job, even with rehabilitation. At this stage, the question for determination is whether the person's work capacity is for a considerable time or permanently reduced. The Act requires that there are causal links between diagnosis and work capacity; inadequate work capacity must be due to a medical condition, rather than to other personal factors such as lack of education or low skills. Factors such as age, education and settlement area should, in principle, only be considered in exceptional cases where special circumstances prevail. Recommendations from the social insurance board state that these circumstances may be considered for older workers.

# Institutional structures and personnel

Medical information is obtained from the person's own doctor. This information is reviewed by the doctor employed by the social insurance institution; however this doctor never examines the applicant. Further information can be requested from the person's own doctor, but the social insurance institution cannot commission its own medical investigations. The role of the doctor employed by the social insurance institution is to act as an advisor to the official handling the case. This official has an important role, particularly in assessing prospects for rehabilitation. The official will often meet the sick person several times during the course of rehabilitation, first when the rehabilitation plan is to be worked out, and later when following up the measures taken.

We can therefore see that this is not a system in which 'medical bureaucracy' plays a significant role. Real decision-making power is vested in the case official: there is no suggestion of always following a medical recommendation.

Decisions on *förtidspension* and other benefits are investigated and prepared by social insurance officials, but the formal decision is taken by the local social security board (there are 15 insurance boards in Sweden; they are not connected to the commune/ local authority). Its members are laymen representing political parties and labour market organisations who are expected to have knowledge about the local labour market and other relevant conditions. The boards can be seen as a check and balance on the discretion of social insurance officers. However, they are criticised, particularly by central authorities, for contributing to non-uniform implementation of social security rules.

Institutions: the social security system has access to vocational rehabilitation services and can finance vocational rehabilitation programmes.

The benefit system is separate to the health care system and the social security system does not determine access to medical rehabilitation or other health interventions, nor does it have any means of financing these interventions. However, the social security system has financial resources to purchase vocational rehabilitation (training, tests, education etc), and the dividing line between medical and vocational rehabilitation is far from clear-cut. For example sick-listed construction workers may be sent to special "back training institutes" in order to recover.

The doctors who write medical certificates are employed in the health care system and chosen by the claimant. If the medical evidence on the certificate is not satisfactory, further information can be requested from the doctor. The praxis is that the certificate indicates the diagnosis as well as the symptoms, but this will depend on the stage the person is at in the health care system - there may be delays in getting the person an appointment with the appropriate specialist. The social security system has to accommodate itself to these delays (Swedish report, q.2).

## Permeability of boundaries: age, social disadvantage

Förtidspension ceases when the old age pension age of 65 (for both men and women) is reached.

The pension age is flexible from age 61, but the guaranteed old age pension is only payable from age 65. A part-time pension with reduced working hours is available from age 61.

For older workers, the line between people with recognised disabilities and those whose employability is low for other reasons is not clearly drawn. For younger workers, the strong orientation towards rehabilitation affects the approach taken. For example, those with literacy and numeracy limitations are liable to be referred to vocational rehabilitation regardless of whether they have a recognised learning disability.

Alcohol addiction: may lead to issuing a medical certificate based on somatic diagnosis, but rehabilitation investigation is again likely to find that person has potential for rehabilitation.

### UNITED KINGDOM

### **Provisions**

The main provision for income support for people unable to work due to illness or injury is *Incapacity Benefit* (IB). IB replaced separate Sickness Benefit and Invalidity Benefit in 1994. There are three levels of IB: short-term lower rate (payable for up to 28 weeks of sickness absence), short-term higher rate (up to 52 weeks) and long-term (over 52 weeks). Many people who become sick when in work receive *Statutory Sick Pay* (SSP) from their employer in place of the lowest level of IB for the first 28 weeks.

The predecessor to IB was *Invalidity Benefit* (IVB). A separate benefit, *Severe Disability Allowance* (SDA), was payable to those disabled from a young age who had an insufficient contributions record to qualify for IVB/IB. SDA was incorporated into IB by amending the IB contribution conditions in 2001, and has now been phased out.

People unable to work due to poor health may also receive social assistance from the general scheme, *Income Support* (IS). Extra amounts ('premia') are payable to people with disabilities receiving IS. However, disability in this context is related to mobility and care needs and does not involve any test of the effect of the health condition on a person's ability to work. Payments for mobility and care needs are discussed in Appendix 3.

### Decision to be made

During the initial 28 period of illness or injury, the test of incapacity for work is based on the person's own occupation:

'The own occupation test is whether he is incapable by reason of some specific disease or bodily or mental disablement of doing work which he could reasonably be expected to do in the course of the occupation in which he was so engaged.'

After 28 weeks, the test applicable is the 'all work test', now called the Personal Capability Assessment (PCA). A person claiming IB having initially been unemployed or having a limited work history is subject to the PCA from the beginning of the claim.

The guidance on the UK IB states that the benefit should be awarded to people whose ability is reduced to the point that they should not be required to seek work as a condition of benefit, rather than the point at which work becomes impossible (UK report, p.1). There is no partial incapacity benefit, although an income top-up (the Disabled Persons Tax Credit) is available to people in work whose earnings are reduced by disability.

## Process of becoming unable to work; employer's responsibilities; rehabilitation

Sickness certification at the beginning of a claim is done by the person's own doctor (the GP). In effect, the GP administers the own occupation test. In practice, GPs 'are rarely in possession of information about the circumstances and demands of their patient's occupation or workplace' (Hiscock and Ritchie, 2001, 18), and certification practices vary widely. While GPs can indicate doubts about the extent of a person's incapacity and call on advice from BA Medical Services, this is rarely done or acted upon. Where a person is receiving SSP rather than IB, it falls to the employer rather than the Benefits Agency to take up issues about the claim. The employer may dismiss the sick worker during the 28 week period, subject to the provisions of the Disability Discrimination Act and subject to rules about the avoidance of SSP obligations (which are rarely invoked).

Medical rehabilitation is undertaken by the National Health Service, vocational rehabilitation by the Employment Service. The social security administration is not involved in organising either form of rehabilitation and does not obtain access to the results of rehabilitation assessments. However, it pays allowances to people undertaking medical and/or vocational rehabilitation.

### Assessment

### - diagnosis

After 28 weeks the GP provides the Benefits Agency with more extensive medical information (Med 4), giving

- diagnosis of the main incapacitating condition
- other relevant medical conditions
- an indication of disabling effects of the condition
- current treatment or progress
- indication of whether patient is able to travel to an examination
- advice given to patient on ability to perform usual occupation.

Statistics on new claims of IB by diagnosis group use the ICD chapters. The top five chapters for new claims in year ended May 2000 were:

V Mental and behavioural disorders

XIII Diseases of the musculo-skeletal system and connective tissue

XVIII Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified

IX Diseases of the circulatory system

XIX Injury, poisoning and certain other consequences of external causes

There is an extensive list of exempt conditions which enable the BA decision-maker to award IB without further evidence, on the basis of the doctor's Med4 report and the client's own application form. For certain other conditions, e.g. severe mental health condition, an award may be made after referring the evidence to BA Medical Services. Further information may also be sought from the GP.

- standardised descriptions of physical or mental capacity
- standardised descriptions of daily life

If an exempt condition is not present, the client is sent a questionnaire (IB50) which is modelled on the PCA. If the self-completed PCA gives the client the requisite number of points (see below) and is consistent with the medical evidence provided by the GP, an award may be made. If there are inconsistencies or the PCA does not give enough points, the client is referred for medical assessment by BA Medical Services. Those with less-severe mental health conditions are referred for a mental health assessment.

The Approved Doctor conducting the medical assessment interviews the client on:

- occupational history and reason for stopping work
- clinical history
- domestic situation
- own account of problems and functional limitations
- how a typical day is spent.

Based on this information, behaviour observed during the assessment, medical knowledge about the effects of the person's condition, and findings of any clinical examination which may be undertaken to select or verify the appropriate descriptor for a person's functional capabilities (see below), the Approved Doctor completes the PCA, or, in the case of mental health problems, the mental health assessment.

The PCA is set out in a Schedule to the Social Security (Incapacity for Work) Regulations 1995. It consists of 14 activities:

walking climbing stairs sitting

.. (other items very similar to the Irish list) continence remaining conscious

Each activity has several 'descriptors' attached to it which indicate the frequency and severity of limitation to the activity, e.g. for speech the descriptors range from 'cannot speak' (15) through 'strangers have great difficulty understanding speech' (10) to 'no problem with speech' (0). Each descriptor has points attached (e.g. as indicated in the brackets).

Part II of the Schedule sets out mental disabilities. There are four activities: completion of tasks daily living coping with pressure interaction with other people.

Each has descriptors attached as in Part I; however the points scale and the way the points are combined are different for this part of the assessment. The guidance emphasises the importance of obtaining indirect insight into the person's mental health by getting relevant information on everyday activities and experience.

The regulations indicate that a person's limitations should be judged in the context of everyday life, rather than specifically in a work situation. Many of the descriptors 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. While appeal decisions have generally upheld the 'everyday' approach, some specific problems have arisen, for example over the regularity and frequency with which a person can perform certain functions, and the problems which may arise from being unable to control the working environment in the same way as the home environment.

The threshold of incapacity for benefit purposes is reached by scoring 10 points on the mental disability descriptors or 15 points from the mental and physical descriptors.

### Institutional structures and Personnel

BA Medical Services are contracted out. The contractor employs Approved Doctors who are registered medical practitioners and have also undergone extra training in conducting PCAs. BA medical services are often criticised by the wider medical community. They do not exercise the discretion that GPs are accustomed to; they are seen as adopting a formalistic and rule-based approach.. However, appeal tribunals and commissioners generally see the Approved Doctors as more disinterested than the client and more impartial than the client's own GP.

Non-medical personnel can make decisions on eligibility where the diagnosis and the claimant's own PCA appear consistent and the PCA shows enough 'points'. However, the arbiters of consistency are the medical personnel who write the guidance and provide advice on claims.

# Permeability of boundaries: age, social disadvantage

The PCA has been seen as a way of preventing people qualifying for IB whose employment prospects are poor, due to e.g. lack of suitable jobs in the area, but who do not have major limitations in functioning. However, the approach to recognised disabilities does not distinguish rigorously between 'social' conditions (to use the Scandinavian terminology) such as alcoholism, and medical conditions.

To some extent, recognised disabilities result in a less tortuous process for claiming. A number of diagnoses give 'shortcuts'; also adjudicating officer is most likely to find consistency between medical certificate and PCA where the diagnosis is familiar and 'traditional'.

Incapacity benefit ceases when the state pension age is reached (currently 65 for men and 60 for women). There is no partial/ early eligibility for the state old age pension (the old age pension is not conditional on retirement, i.e. does not require recipients to cease work).

### **ANNEX**

# Standard classifications of medical diagnoses and impairments

## International classification of diseases - 10th revision (ICD-10)

The ICD-10 is organised as follows:

## ICD-10 chapters

- I Certain infectious and parasitic diseases (A00-B99)
- II Neoplasms (C00-D48)
- III Diseases of the blood and immune system (D50-D89)
- IV Endocrine, nutritional and metabolic diseases (E00-E90)
- V Mental and behavioural disorders (F00-F99)
- VI Diseases of the nervous system (G00-G99)
- VII Diseases of the eye and adnexa (H00-H59)
- VIII Diseases of the ear and mastoid process (H60-H95)
- IX Diseases of the circulatory system (I00-I99)
- X Diseases of the respiratory system (J00-J99)
- XI Diseases of the digestive system (K00-K93)
- XII Diseases of the skin and subcutaneous tissue (L00-L99)
- XIII Diseases of the musculo-skeletal system and connective tissue (M00-M99)
- XIV Diseases of the genito-urinary system (N00-N99)
- XV Pregnancy, childbirth and the puerperium (O00-O99)
- XVI Certain conditions originating in the perinatal period (P00-P96)
- XVII Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)
- XVIII Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified (R00-R99)
- XIX Injury, poisoning and certain other consequences of external causes (S00-T98)
- XX External causes of morbidity and mortality (V01-Y98)
- XXI Factors influencing health status and contact with health services (Z00-Z99)

## Notes:

The chapter XXI 'Z' codes include problems related to lifestyle, e.g.

Z72.0 Tobacco use; tobacco dependence is under F17.2 (chapter V);

Z72.1 Alcohol use; alcohol dependence is under F10.2 (chapter V).

ICD-10, Vol 1, WHO 1992

# **Impairments**

The chapter headings for impairments in ICIDH-1 are:

- 1 Intellectual
- 2 Other psychological
- 3 Language
- 4 Aural
- 5 Ocular
- 6 Visceral
- 7 Skeletal
- 8 Disfiguring
- 9 Generalised, sensory and other

This particular set of headings is rarely found in national assessment rubrics. A more common approach is to use organise the scheme by diagnostic headings, with protocols for assessing the degree of impairment which results from the diagnosed condition. A leading example of an impairment-based approach to disability determination is that developed by the American Medical Association, which defines disability as: 'an alteration of an individual's capacity to meet personal, social or occupational demands, or statutory or regulatory requirements, because of an impairment'. This definition puts the focus on impairment; the scope of disability is very wide and general. The chapters in the AMA Guides to the Evaluation of Permanent Impairment (American Medical Association, Chicago, 1993) are:

Musculo-skeletal
Nervous
Respiratory
Cardiovascular
Hematopoietic
Visual
Ear-nose-throat (including speech)
Digestive
Urinary and reproductive
Endocrine
Skin
Mental and behavioural
Pain.

It can be seen that these headings are more related to the diagnostic headings in ICD-10 than the impairment headings in ICIDH-1, although there is some overlap between all of them.

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# **Appendix 2 Definitions in Employment Provisions**

Member States of the EU have a wide range of measures intended to promote the employment of disabled people. The provisions include:

- Quotas, sometimes accompanied by a levy for unfilled quota places;
- Temporary or permanent wage subsidies, adaptation grants (paid to employers) and income top-ups (paid to workers);
- Training and rehabilitation services, and/or fee payments and living allowances for people in training and rehabilitation;
- Placement services, job coaching, assistance with interviews, interpreter services etc.

The processes by which people come into the ambit of employment services, and decide whether or not to apply for access to special provisions for the disabled, or are channelled to those provisions, involve both individual incentives and institutional considerations. Looking first at individual incentives, no state in the EU requires people who have already been awarded disability benefits to make contact with providers of employment services as a condition of maintaining their benefit. There is thus considerable scope for discouragement effects among disability benefit recipients. On the whole, the national reports suggest that the people who seek employment services are not in receipt of disability benefits, although they may be 'en route' to the eventual award of disability benefit.

Conditions for access to other cash benefits (possibly en route to long-term disability benefit) may affect the number of disabled people using employment services. Several states offer employment services, particularly vocational rehabilitation, to people who may eventually be eligible for disability benefits. For example, Germany applies the principle of 'rehabilitation before pension' while the Danish municipalities are strongly incentivised to explore employment options before making a long-term disability benefit award.

People may also be pressed into special programmes for the disabled if the conditions for unemployment benefit receipt are such that they cannot maintain the status of an 'ordinary' unemployed person. Conditions requiring a person to be available to work more than a specified number of hours a week, or to have sufficient 'capability to work', exist in most of the Member States. The states vary considerably in the destinations for people excluded from unemployment by such rules: in some states the person may utilise employment services for the disabled whereas in others such options are not provided. For example, in Germany the person may become a 'rehabilitant' if a suitable programme is available; in other states social assistance or short-term sickness benefit may be a more common destination, at least while a disability benefit claim is being processed.

In the country-by-country analyses, we have summarised these different factors by giving an overview of provisions and an account of the individual and institutional incentives and requirements that they engender. Under the headings of <u>Institutional responsibilities and linkages</u> and <u>Incentives and requirements to participate in measures</u>, the analyses seek to explain the relationship between mainstream employment measures and the employment provisions for disabled people under discussion. Any available information about institutional incentives around the disability classification is included, along with a summary of the benefit rules and other requirements which may affect an individual's decision to put himself or herself forward for measures.

Other elements of the assessment process are summarised under the following headings:

### Personnel

E.g. whether people involved have employment-related skills or medical expertise.

#### Rules and instruments

### Observation in context

There may be opportunities for assessors to observe people in the workplace or engaged in specific work-related tasks, whether in a mainstream employment environment, a sheltered workshop, or a rehabilitation institution.

### Role of disabled person

Disabled people themselves may have a role in the assessment, which may include the opportunity to indicate their aspirations and preferences, as well as making the more general decision of whether they wish to be classified as disabled or not.

## Role of employer(s)

Employers may e.g. encourage existing workers to apply for classification, or be represented in bodies governing the work of the assessing institution.

All information relates to 2001, when the national reports were being written. Where applicable, changes introduced before 1 Jan 2002 are noted.

#### **AUSTRIA**

#### **Provisions**

The employment provisions discussed in the national report are:

1. The Disabled Persons Employment Act (BEinstG) which includes the quota scheme, rules on non-discrimination in wages, dismissal protection, subsidies, loans etc, along with provisions on supported employment and integrative firms.

Supported employment: assistance in finding a job in the open market - provision of job coaches, vocational development, administrative support, information etc for employers about how to accommodate the person.

Integrative firms - previously called sheltered workshops - change of name to emphasise that work experience should enable users to go on to a job in the open labour market. Remuneration etc corresponds to that provided under mainstream collective agreements.

Note that provincial governments also operate sheltered workshops, occupational therapy facilities etc under their own competences, often with different rules on remuneration, financial self-sufficiency and subsidies, etc.

2. The Labour Market Service Act (AMSG) (1994) which provides employment services for working age people generally, with special mention of those who have disadvantages in the labour market and whose employment opportunities are not equal to those of others (s.31). Special training programmes are available to disabled people and there is a higher budget for measures for them.

In addition, the social insurance system and the Accident Insurance Agency provide rehabilitation to people who cease work due to illness/ incapacity and have sufficient contributions to qualify. This provision is oriented primarily to medical rehabilitation.

## Institutional responsibilities and linkages

Official documents testifying to a *Grad der Behinderung* (GdB) of 50%+ can be obtained from several institutions, including the social insurance agencies and the Accident Insurance Agency. In the absence of involvement of one of these agencies, the Federal Office of Social Affairs is responsible for certification. There are also elements of certification by supported employment providers and integrative firms themselves.

Integrative firms are geared towards the registered disabled, but this does not mean either

- (a) that a registered disabled person has a right to a place in an integrative firm access depends on the location of specific firms and the vacancies that arise; a waiting list is maintained: or
- (b) that the integrative firm must only employ registered disabled people. Instead it works to wider parameters: 80% of employees must be people with a disability (GdB of 30%+) and 60% must be registered (50%+).

People taking up Supported Employment places have to be capable of integration onto the open labour market. SE providers must meet targets regarding successful placement. They have incentives to reject people who are hard to place but this is not done in a formal way (e.g. by setting a minimum work capacity requirement), by contrast with integrative firms (see p.5 below).

## Labour Market Service

For the Labour Market Service, disabled are one group among the 'hard to place' (*schwervermittelbar*). The 'disability path' is not always chosen as most suitable. However, there are budgetary advantages to using the disability path.

## Incentives and requirements to participate in measures

Obtaining a disability (GdB) assessment entitles a person to a range of measures under the BEinstG and to some extent also under the AMSG. All these measures relate to employment - there is not much reason for a person who is not in employment or seeking work to obtain an assessment. There is some evidence that a high proportion of those who seek registration under the quota are already-employed workers who become disabled.

A person cannot obtain access to any Labour Market Service provisions without sufficient 'capability to work' (*Arbeitsfaehigkeit*).

### **Assessments**

# Registration as a disabled person under the BEinstG (quota system etc)

### Decisions to be made, criteria

- measurement of severity of impairment:
   The person's degree of disability (GdB) is measured out of 100; eligibility depends on achieving a score of 50+. The GdB is not intended to measure work capacity or incapacity.
- limitations in performance of general employment-related activities

  However, a person cannot be registered as disabled if the disability is so severe that
  integration into the labour market is not possible. This decision is made by the
  assessing doctor (see below).

#### Personnel

Medical records are provided by the applicant; normally there is a further examination by a doctor employed or commissioned by the responsible agency (usually the Federal Office for Social Affairs, BSB). The doctor reports on the person's health and impairments but does not provide an assessment of ability to work, except in the above-mentioned case where the disability is so severe that integration into the labour market is not possible.

#### Rules and instruments

The basis for the doctor's report is the *Richtsatzverordnung* (RSV), a detailed list of impairments (725 items) with corresponding percentages of disability. There are rules for combining the percentages for different impairments into an overall rating.

### Observation in context

None, but see below in relation to integrative firms and sheltered employment.

## Role of disabled person

The disabled person must initiate the process of registration.

# Role of employer(s)

None in the assessment of GdB.

### Other assessments under the BEinstG

### Integrative firms

## Decision to be made/ criteria:

Integrative firms are geared at registered people with disabilities. However, people with disabilities who are not registered can count towards the firm's fulfilment of its targets if their degree of disability is greater than 30%. This is assessed by the firm's doctor using the RSV, who also indicates the tasks the person would be suited for (see below - remaining capacity). The doctor reports to an assessment team comprising representatives of the firm, the Labour Market Service, Federal Office of Social Affairs, Provincial Governments etc. This team oversees the process of putting people on the waiting list and allocating places in the light of the person's type of disability, qualifications and work experience.

For access to integrative firms there is a further criterion of 'remaining work capacity' (*Restleistungsfaehigkeit*). The person must have at least 50% of normal work capacity.

A person's place on the waiting list depends on the date of application, but also on qualifications, development potential and 'social urgency' (meaning how important it is for the person to find employment).

#### Rules and instruments

Remaining work capacity is assessed by the firm itself by observing the person's performance in an actual job. The degree of remaining work capacity can change if the person's job changes.

**Supported employment**: while registration as disabled (GdB > 50%) gives access to these provisions, they are also open to other groups. Supported employment providers are often oriented to particular disabilities (e.g. deafness).

### Observation in context

Checklist of functional impairments - may be completed by the assistant/ coach after spending time working with the applicant. Clients may be asked to complete a vocational orientation questionnaire.

Assistant/ coach makes report after spending time working with the applicant. Trial work days may be used in order to do the assessment.

### **Under the AMSG (labour market measures)**

### Decision to be made/ criteria

If a person has an assessment under the BEinstG (registered disabled, or 30%+ disabled) then this is sufficient for eligibility for special support under the AMSG

Otherwise, the Labour Market Service staff member makes a decision as to whether to take the 'disability path' taking into account:

- personal and social circumstances specific to the person
- self-assessment of the client
- views of others e.g. trainers
- possible stigmatising effect

#### Personnel

Evidence of medical history is required. An examination is usually commissioned from an official public doctor (*Amtsaerzte*) (e.g. doctors of the Red Cross in Vienna). The doctor's report suggests where and how the person might be able to work and contains recommendations on e.g. special training.

The personnel of the Labour Market Service varies by region, e.g. in some places there are specific vocational rehabilitation services and specialists in this field whereas in other centres these tasks are done by the ordinary staff.

### Rules and instruments

There are no specific instruments. There are very substantial regional differences in the use of the 'disability path' particularly for people with mental illnesses. The intention is that staff choose an individual approach for each client which is tailored to his or her needs.

The labour market statistics used to indicate the type of disability (physical, sight, hearing, mental, learning) but now (since Sept 99) only indicate the type of registration a person has. Largest category is 'otherwise recorded by the Labour Market Service'.

### Observation in context

The assessment is made in the light of possible suitable labour market service provisions (e.g. training possibilities).

### Role of disabled person

The person in question must agree to the disability path being taken.

Role of employer(s)

None.

### **BELGIUM**

### **Provisions**

The employment provisions discussed in the national report are those of the Flemish Fund for the Social Integration of Persons with a Disability. Similar provisions are made by other regional funds such as the Walloon Fund (AWIPH). The provisions include:

- wage subsidies
- vocational training
- sheltered employment
- provision for an interpreter or other assistance

## Institutional responsibilities and linkages

Employment services are a devolved responsibility in Belgium. The National Employment and Placement Service (RVA/ ONEM) administers unemployment benefits but does not have any placement responsibilities since the 1991 devolution reform. The responsibilities of the National Fund for the Social Rehabilitation of the Disabled were also devolved from 1.1.91.

The Flemish Fund finances a range of interventions including care services and equipment. Only the employment provisions are discussed here, but note that some social service provisions made by the same Fund may operate in effect as employment measures, e.g. the provision of help to a person for getting to work.

Institutionally, the Flemish Fund and its regional counterparts are quite separate from other employment-promoting institutions, such as employment exchanges.

## Incentives and requirements to participate in measures

There are no explicit links between employment services for the disabled and income support measures. The most common situation for a person who applies for employment aid to the fund is that the person is on unemployment benefit (UB). School-leavers as well as people who have been in work are eligible for UB in Belgium.

People with disabilities may be classified as 'hard to place' by the regional placement services. However, this does not result in exclusion from receipt of Unemployment Benefit; on the contrary, UB may be paid to the hard-to-place for longer than for 'ordinary' unemployed people. Recent years have seen increased efforts to 'activate' people who are long-term unemployed, including some joint arrangements between the Flemish placement service and the Flemish Fund for Social Integration of Persons with a Disability. However, these efforts are not accompanied by any emphasis on the use of sanctions against those who remain out of work.

The report comments that the numbers of people putting themselves forward, and being accepted onto, measures depends on what is available. 'The more types of provisions or services the Fund develops, the more people are likely to be administratively labelled as disabled.' (Belgian report, p.13)

#### **Assessments**

#### Decision to be made, criteria

The claimant has to be a 'disabled person' where a disability is defined as a 'long-lasting and substantial limitation of the possibilities of social integration due to reduced intellectual, psychological, physical or sensory capacities'.

- limitations in performance of general employment-related activities
   In the area of employment provisions, what is assessed is the extent to which a person's reduced capacities hamper integration into the labour market.
- indicators of disadvantage, e.g. difficulty in obtaining employment In the absence of a 'strong' diagnosis, e.g. where person has a mild condition, applicant needs to present evidence of failed attempts to find a regular job
- limitations in performance in a specific job

There are two schemes for subsidised employment: CAO-26 (Collective wage agreement 26) or VIP (*Vlaamse Inschakelingspremie* - Flemish integration grant). The latter is a recent measure which differs from the CAO-26 because the level of subsidy is constant (30% of the minimum wage in the particular sector), whereas for the CAO-26 it varies between 5% and 50% of the wage, depending on the extent to which the worker's productivity in the particular job is below normal productivity.

In the case of the CAO-26 the measurement of loss of productivity is contextualized (measured in a specific work-setting). If a person is deemed ineligible for the specific provision, the general assessment becomes void. For VIP the measurement of loss of productivity is not contextualized: the status is given after the general assessment and even before the person has a job.

### Personnel

General eligibility is assessed by multidisciplinary commissions on the basis of information provided by multidisciplinary teams working in accredited non-profit organisations.

Eligibility in the context of specific provisions involves other actors, notably the Inspectorate of Labour Laws, which determines the level of CAO-26 subsidy which should be paid to the employer of a disabled worker in a particular job. The Inspectorate is not involved in administering the VIP subsidy.

### Rules and instruments

In some cases, e.g. if person is deaf, evidence of impairment in itself is sufficient to be granted the relevant provision (assistance by an interpreter at work).

In principle every form of aid provided by the fund depends on an individual decision by a commission based on an individual measurement of need. However, in some cases rules have been formulated to aid internal decision-making, although they have no legal status and could be overturned if appealed against. For example, measures made available to school-leavers are, in the first instance, based on the client's educational level and history.

### Observation in context

The initial assessment procedure is conducted 'out of context' and determines whether the person is allowed to work in a sheltered workshop, is disabled enough for his employer to receive a wage-subsidy, etc. The person then has a 'ticket' for one or other provision. The 'ticket' may remain unused because e.g. the holder has no job for the moment or the workshop is full. However when the person finds a placement, then the employer or the workshop may turn to the Fund to receive financing for the person.

In the case of the CAO-26 subsidy, the 'ticket' is in effect revisited and the Inspectorate of Labour Laws makes an on-site inspection.

## Role of disabled person

The disabled person initiates the application by asking the Flemish Fund for help in integrating into the labour market, either in general terms or for a specific service, such as a place in a sheltered workshop or adaptations to a workplace or for his/her employer to be awarded a wage subsidy.

## Role of employer(s)

In practice the Labour Inspectorate's decision on a CAO-26 subsidy often comes down to a matter of negotiation with the employer.

#### **DENMARK**

#### **Provisions**

The provisions discussed in the national report are:

The Law on Active Social Policy (1998) which provides for vocational rehabilitation and 'flexjobs'. Flexjobs are jobs with wage subsidies of 25%, 50% or 75% of the minimum wage (the 25% band will be eliminated in 2003).

There are also 'protected jobs' which carry a 50% subsidy, where the person works for 1/3 of normal time.

The Law on Compensation to Persons with Disabilities in Employment (LCPDE) provides for:

- 1. Preference for workers with disabilities in the public sector:
  - in practice, only a few authorities apply the preference law in their appointments;
  - however, the law is applied in licensing for stalls and taxi-driving.
- 2. Icebreaker scheme: a subsidy scheme for new entrants into employment with disabilities
- 3. Scheme for payment for work aids, tools and improvements in accessibility
- 4. Personal assistance scheme normally up to 20 hours per week, but in some cases full-time

## Institutional responsibilities and linkages

The Employment Service administers LCPDE; other measures are administered by the municipalities. The municipalities have the key role in managing the provision of rehabilitation and the award of benefits. They have considerable discretion in decision-making. They have a strong financial incentive to arrange 'flexjobs' for people who would otherwise be receiving rehabilitation allowances, foertidspension or social assistance, as the subsidy is paid by central government.

The take-up of employment under a social chapter (allowing variation to terms and conditions of employment for people with reduced capacity) is determined by the employer in agreement with the union which negotiated the chapter.

## Incentives and requirements to participate in measures

The Law on Active Social Policy is motivated by the desire to reduce numbers of people claiming benefit and ensure that those claiming are encouraged to seek work. The principal target of the measure was unemployed people; initially focus was on the young unemployed.

The law covers all who present themselves at a municipal office for assistance. The distinctions between those whose limitations in obtaining employment are due to disability and those affected by other problems (e.g. lack of education, addiction etc) are made by the municipality in the course of determining appropriate measures (activation, rehabilitation etc).

Current provisions emphasise the exploration of employment options before disability pension is awarded. However, protected jobs (employer receives 50% subsidy), are for people in receipt of a disability pension.

In some ways, the treatment of disabled people seeking employment is similar to that of any other group of people who have difficulty obtaining employment. The central organisation of disabled people, DCODP, does not argue for differential treatment in the application of activation and rehabilitation policies. DCODP advocates a model of compensation, whereby people with reduced functional capabilities should be compensated in a way which enables them to function on an equal footing with others.

To some extent, this concept is reflected in the LCDPE. LCPDE measures are oriented towards people with physical disabilities.

### Assessments

# **LCPDE**

Decisions to be made, criteria

LCPDE defines its user group as 'persons with disabilities' but does not define them further, except for the personal assistance scheme, where certain conditions are mentioned specifically (blindness etc - see below).

The Equal Opportunities Centre has put forward a definition of disability which seeks to incorporate the principle of compensation, which, it argues, is the principle behind the LCDPE. Its definition is that a person is disabled if there is

- a physical, psychic or intellectual reduction of functions that causes a need for compensation if the person is to function on an equal footing with other citizens in a comparable life situation.
- limitations in performance in a specific job
   The nature of the measures under LCPDE, especially workplace adaptations, directs attention to limitations in a specific job/ workplace.
- indicators of disadvantage, e.g. difficulty in obtaining employment
   The person seeking assistance must be hard to place, i.e. have failed to get a job under normal conditions.

### Personnel

Employment Offices employ special disability counsellors, originally appointed in connection with the Social Responsibility of the Enterprise campaign

A medical certificate is required; this is provided by the person's own doctor.

#### Rules and instruments

Three impairments are mentioned specifically for the personal assistance provisions - visual impairment, hearing impairment and limitations to physical functioning (meaning specifically paraplegic etc).

For the other provisions, there is no detailed guidance on assessment.

#### Observation in context

For the provision of workplace aids, the determination of access to the provision depends on the suitability of the service to the person's needs.

## Role of disabled person

Whereas 'activation' measures can be compulsory, disabled people must seek out measures under the LCPDE.

## Role of employer(s)

Employers have no legal obligations to facilitate take-up of LCPDE measures; the 'social responsibility of the enterprise' campaign has sought to persuade them to do so. This initiative sought to promote the employment of disabled people through 'persuasion' and the inclusion of 'social chapters' in collective agreements under which people of less than 100% fitness could be taken on.

### Measures under the Law on Active Social Policy:

#### Decisions to be made

The Law on Active Social Policy provides for rehabilitation and flexjobs for those whose working ability is reduced. Working ability is defined as 'the ability to fulfil the demands of the labour market to do different specified tasks in order to gain an income'.

The law covers all who present themselves at a municipal office for assistance. The distinctions between those whose limitations in obtaining employment are due to disability and those affected by other problems (e.g. lack of education, addiction etc) are made by the municipality in the course of determining appropriate measures (activation, rehabilitation etc).

#### Personnel

The key decisions are made by social workers.

### Rules and instruments

Measures are notable for their reliance on the financial incentive structure to influence municipal decisions, rather than the use of centrally-determined rules and instruments.

### Observation in context

Everyone who is long-term sick should have a rehabilitation plan; rehabilitation institutions may observe and assess the claimant.

The rate of subsidy in a job will in practice often be determined by the person's observed capacity in that job.

### **FINLAND**

### **Provisions**

The employment provisions discussed in the national report are those coming under the Law on Employment Service and the Regulation concerning the Employment Service, which includes provision for:

- special help with placement and vocational counselling
- training grants
- grants for work trials
- subsidies to employers: the job can be subsidised for up to 24 months (compared with six months for other groups of jobseekers e.g. the long-term unemployed) and the subsidy can be paid from the onset of job search, while for other target groups some minimum spell of unemployment is needed (usually five months) before the scheme is applicable.

There are also several employment-related measures which are linked to social insurance. Particularly important are the measures which enable a person to remain in employment after the onset of long-term sickness/ disability, including the provision of workplace adaptations, training courses etc, called maintenance of work ability (MWA). Thus, vocational rehabilitation for those with lowered work ability or threat of lowering work ability is funded by social insurance (in Finnish the acronyms of TYK and ASLAK, respectively). Another measure, the Employment Related Disability Allowance, compensates disabled people in employment, training or job search for extra costs caused by disability. Here, the definition of disability is impairment-related and the compensation has three levels, depending on the severity of the impairment.

## Institutional responsibilities and linkages

Delivery of the provisions discussed here is by the Employment Service, which is under the control of the Ministry of Labour.

Sheltered employment places are provided by the municipalities and NGOs, and do not have much connection with the provision of employment services. Municipalities also provide facilities for drug and alcohol addiction. Sheltered employment is available in a number of forms in Finland, it has a very small role as a means of employment policy, and its mainly functions as a social integration/ inclusion measure for, e.g. intellectually disabled people.

Linkages to mainstream ES measures and measures for other groups with labour market disadvantages are important - mainstream services are available to people with disabilities and may often be more appropriate than special services. The advantages of being recorded as disabled are today questionable. The focus of ES activity has shifted towards other groups (long-term unemployed, young unemployed, immigrants). The main advantage is quick access to a 24 month subsidy. Some authors have questioned whether ES registration as disabled serves any function, as disabled jobseekers fare badly in terms of e.g. duration of unemployment. Furthermore, registration may be considered stigmatising.

The idea of registration is not to segregate disabled jobseekers but to make additional services available to them, as described above.

## Incentives and requirements to participate in measures

Those over 50 and in the process of early retirement through early pension schemes have not been pressed to take up ES measures for the disabled. This is due to the utilization of pension policy as a solution to aged jobseekers' labour market problems. The situation is now changing, there is a strong emphasis on increasing the participation in the labour force, but it is too early to comment on the outcomes of the development, from the point of view of the disabled.

Due to the interaction of pension and employment policy, at the individual level, there may also be a trade-off between unemployment benefits and pensions. As a rule, a disabled person does not lose unemployment benefits through insufficient work capacity or availability for work by reason of disability. However, he or she may lose the benefit for refusing without due cause the job offers of the employment service, as for any jobseeker. Sometimes a person may have been certified as disabled and entitled to a disability pension, however, the application procedure takes some time and there may be gaps between the receipt of benefits.

#### Assessments

### Decisions to be made, criteria

Disabled people are defined in accordance with ILO Convention 159, as "persons whose prospects of securing, retaining and advancing in employment are substantially reduced as a result of a duly recognized physical or mental impairment".

Impairment per se is not sufficient to qualify: a person's employability must be affected - e.g. loss of limb may be irrelevant, if a person has an academic background. Functional limitations are taken into account if they are documented diagnostically and bear an influence on work ability.

#### Personnel

The person's health problems have to be documented with a medical certificate. This is obtained by the applicant. The ES does not have a medical service; nor does it commission medical reports, but it may advise the jobseeker to seek medical help and be certified.

Roles of different professionals: psychologists engaged in vocational counselling implemented an expansive definition of disability; since 1998 medical diagnosis is required which may be one of the factors behind reduced use of the disability path in vocational quidance.

### Rules and instruments

No standardised instruments: flexibility of the employment authorities is wide, exercised in principle on the basis of whether classification as disabled will benefit the client.

ICD codings are maintained and used for the annual statistics of the Service.

### Observation in context

No opportunity for observation in context except in so far as this is implicit in ascertaining that measures available are suitable for the client.

### Role of disabled person

No entry into the file concerning disability is made without the consent of the client.

### Role of employer(s)

No employer role in the provisions of the employment service, generally (most disabled jobseekers are unemployed, and those not unemployed have registered in the employment service anticipating future unemployment). However, in the MWA the employers' role is of key importance.

### **FRANCE**

### **Provisions**

The employment provisions discussed in the national report are a set of legal opportunities which facilitate access to, and maintenance in, employment for people recognised as *travailleur handicapé* (TH). The provisions include:

- 1. In mainstream employment:
- the GRTH (guarantee of resources to the handicapped worker): the employer pays the TH the full wage, but receives a refund of a portion of the wage (complement of remuneration):
- a recruitment bonus for the employer and for the worker (prime a l'insertion).

TH are assessed in three categories of disability: A (mild), B (moderate) and C (severe). Firms can pay a reduced wage to people in categories B (up to 10% reduction in normal wage) and C (20%).

- 2. In protected employment (ETP), complements are also payable, at higher rates. Protected employment comprises 'social firms' for those less severely disabled (1/3+ of normal capacity), and sheltered workshops (*centres d'aide par le travail*, CAT) for those more disabled.
- 3. In vocational training, fees for the trainer and training allowances for the worker are payable.

TH count towards the fulfilment of the quota which operates in mainstream employment. The employer's obligations under the quota can be met by:

- employing workers classified as TH;
- making contracts with establishments providing protected employment (ETP);
- concluding agreements/ plans with AGEFIPH (see below);
- paying a levy to AGEFIPH.

## Institutional responsibilities and linkages

The main institution responsible for promoting the employment of disabled people is AGEFIPH (see agefiph.asso.fr), which obtains its income from levies paid in default of the quota. AGEFIPH administers the GRTH (since 1996) and other expenditure programmes, and finances the *Cap emploi* network of employment service providers (comprising EPSR and OIP). It also concludes agreements with major employers, providers of training, and related agencies such as ANPE (the employment service).

Linkages to mainstream ES measures and measures for other groups with labour market disadvantages: The presence of a separate assessment agency (COTOREP) and a separate fund for promoting the employment of the disabled (AGEFIPH) suggests that provision for the disabled is quite separate to mainstream provision. However, AGEFIPH has concluded some agreements with mainstream providers of employment services.

# Incentives and requirements to participate in measures

No links with the benefit system; workers may seek TH status when they are unable to hold down their present/ previous job but are not sufficiently disabled to obtain an invalidity pension. This particularly applies to workers reaching the end of the sickness benefit period (3 years), especially those who have utilised its provisions for a partial return to work, which have a maximum duration of six months.

As well as those assessed by the COTOREP, people can also be recognised as TH if they have a work injury and industrial disease causing a disability of 10% or more or an invalidity pension (from the Sécurité Sociale) involving a loss of capacity of 2/3+.

#### **Assessments**

### Decisions to be made, criteria

A TH is 'an individual whose prospects of obtaining or keeping employment are effectively reduced by a loss or insufficiency of physical or mental capacity'. A person seeking access to measures relating to employment applies for assessment as a TH to the first section of the COTOREP. This section assesses the person's work capacity; it does not use the 'guide bareme' (see WP1). The COTOREP can refuse an application if the person's capacity is not sufficiently reduced or if it considers that work is impossible. Some 40% of first applications are rejected.

### Personnel

The initial medical statement is provided by a doctor chosen by the claimant, who has no link with the COTOREP. For TH applications, the doctor may be the workplace doctor.

The technical staff of COTOREP comprise doctors, work psychologists, social workers and staff from the unemployment office. They may seek further information from specialists.

### Rules and instruments

The Guide Bareme is not used for assessments by the first section, concerned with professional orientation. There are no formal guides and instruments which are publicly available.

### Observation in context

Where a person is not employed, there is no opportunity for observation in context, and the assessments of the COTOREP are criticised for being rather abstract. The orientation decided on by the COTOREP may not correspond to any actual opportunities or places open; in particular, 'the orientation to mainstream employment means an orientation to the unemployment office' in many cases (French report, p.26).

However, an application may be made by a person already in employment or considering taking up a specific job. It is clear from AGEFIPH guidance that employers may seek financial support for workers who do not initially have TH status. For example, the description of the process of obtaining the wage complement includes an account of the process for getting a worker classified as TH.

## Role of disabled person

Applicants for an assessment indicate what they are seeking: in general whether they are seeking recognition as a TH or eligibility for benefits (which determines whether the application goes to the first or the second section), and, if TH, whether they are seeking orientation to mainstream employment, training or sheltered employment, etc.

While the Labour Code provides that a person can put his or her case in person and discuss the appropriate orientation with the Commission, in practice such meetings are rare. However, the technical staff discuss the case with the applicant.

## Role of employer(s)

Employers may be important in encouraging the initiation of applications by their own workers who experience the onset of a disability, or by prospective workers. One effect of the quota is to give employers incentives to identify disabled workers, although many just pay the levy.

Employers, along with union representatives, are found on the Commission which is responsible for the final decision. In practice, its authority is often delegated to the technical personnel of the COTOREP.

#### **GERMANY**

### **Provisions**

The main employment provisions for disabled people in Germany are:

- Rehabilitation services financed by the employment service (BA), pensions institutes, and municipalities (*Sozialamt*, *Jugendamt*);
- Extensions to the general training services provided by the BA, e.g. longer training periods for disabled people;
- The quota and additional measures connected with it.

These provisions apply to two different target groups: rehabilitation services and extended employment services are available to those loosely defined as disabled, while the quota is targeted on the 'severely disabled' (*Schwerbehinderte*) and those with 'equal status'. The two definitions are quite different, and do not really relate to the 'severity' of the disability, as explained below.

Note also that the extended services of the BA are entirely concerned with preparation for work (training, rehabilitation etc) and do not include assistance in the workplace. Employment measures for the severely disabled, on the other hand, are focused on the workplace. Although members of this group may also qualify for rehabilitation and training, they are separately assessed for such measures.

The quota system (*Pflicht zur Beschaeftigung schwerbehinderter Menschen*) was substantially reformed from 1 Jan 2001. The main motivation was that many companies were paying the levy rather than endeavouring to comply with the quota. The main changes were a reduction in the quota rate (from 6 to 5%), coupled with increased penalties for non-compliance. Penalties are now graduated so that firms which fail the most (those which employ fewer than 2% of severely disabled workers) pay a higher rate per quota place unfilled.

At the same time, provisions for financial aid (integration subsidies) to companies employing severely disabled workers were made more generous, and the institutional structure for delivering that aid was reformed. The government launched an initiative for '50,000 jobs for the severely disabled' to be created. It has stated that, if unemployment among severely disabled workers is not lowered by 50,000 by October 2002, the quota will be raised again in 2003.

Integration subsidies cover a percentage of the employee's pay for a period of initial employment with the firm, where this can be designated a 'training period'. The subsidy may last up to 24 months and is paid at a rate between 40-60%. Grants for workplace adaptations can also be paid.

## Institutional responsibilities and linkages

Access to rehabilitation services (Reha) can be channelled through the social insurance system, other social service institutions or through the BA. A number of measures have been taken to address the complexities of assigning responsibility for financing rehabilitation between these institutions, for example through the creation of *Gemeinsame Servicestellen fuer Rehabilitation*. The modus operandi of these 'service centres' is that appropriate rehabilitation is assessed and initiated quickly, and issues about who should pay for it are resolved subsequently.

Within the BA, access to Reha and eligibility for extended training etc require an assessment by the BA Medical Service.

The BA also operates mainstream employment services, which are open to people leaving medical rehabilitation or with other health problems, as well as to the 'ordinary' unemployed. For example, those seeking a change of occupation after a serious illness may be referred to the BIZ (*Berufs-Informations-Zentrum*) in the BA, which provides information to all jobseekers. Severely disabled people are also encouraged to make use of the BIZ (see www.jobs-fuer-schwerbehinderte.de).

Administration of the quota and other measures for the severely disabled involves special units in BA offices called 'integration speciality services' (*Integrationsfachdienste*). These services are described as 'supporting' the labour offices and they have financial autonomy, with budgets managed by the Integration Offices (*Integrationsaemter*).

Assessment of severe disability is not done by these offices but by the *Versorgungsamt* (sometimes referred to as the *Amt fuer Versorgung und Familienfoerderung*) which comes under the competence of the *Länder*. The *Versorgungsamt* determines a person's disability rate (GdB), and those with a rate over 50% count as severely disabled. However, the labour offices determine whether people with rates of 30-50% should be treated as having equal status (*gleichstelle*) for the purposes of the quota.

### Incentives and requirements to participate in measures

There is no relationship between obtaining a disability card (GdB > 50) and eligibility for the main cash benefits. However, minor benefits are awarded, such as ..

If the person's capacity is so limited that he or she cannot work for more than 15 hours per week, then availability for work is inadequate to register as unemployed. In principle, the BA Medical Service may determine that the relevant Pensions Institution is liable to pay for benefits. Since the Pension Institutes operate the principle of 'rehabilitation before pension', they may develop a Reha plan. In some cases (where people have less than 15 years contributions history), the BA is liable to finance the Reha plan. Such people are classified as 'rehabilitants', not as unemployed (or as pensioners)..

Reha services are available to recipients of unemployment insurance and assistance, as well as to social assistance recipients.

#### **Assessments**

## **Severe Disability**

### Decisions to be made, criteria

- measurement of severity of impairment
   The Versorgungsamt assesses a person's overall disability rating (GdB) out of 100. The
   GdB is intended to measure limitations of a person's life chances (Beeintraechtigung der
   Teilhahme am Leben). It does not reflect working ability and is independent of the
   person's occupational history and aspirations. The impairment has to be atypical for a
   person of that age to be recognised.
- limitations in performance of general employment-related activities In determining whether a person with a GdB of 30-50 should have 'equal status', the labour office considers whether, without equalisation, the person will not be able to obtain a suitable job due to the handicap. Only qualification for the quota flows from equalisation; other benefits such as travel concessions and extra holiday are not awarded.

### Personnel

The decision on the GdB is entirely based on medical data and knowledge.

### Rules and instruments

The *Versorgungsamt* utilises a barema which indicates, for each impairment, a corresponding degree of disability. Overall ratings are calculated from impairment scores in each 'area' (spine and lower legs etc).

#### Observation in context

None in determining the GdB; note however the increased attention to the placement/ job matching process (below).

## Role of disabled person

The disabled person must apply for an assessment. The official website www.jobs-fuer-schwerbehinderte.de urges disabled people not to try to do without the document of identification as severely disabled, as otherwise they will not be able to take advantage of their rights.

The website goes on to encourage disabled people to 'assess themselves' i.e. to consider their occupational aspirations and restrictions, whether they want to work by themselves or in a team, etc.

Disabled people are also encouraged to visit the Labour Office, even if they have been before, as new measures are now available, and to use the occupational information centre (BIZ).

## Role of employer(s)

The 2001 reforms involved some changes in the relationship between employers, the disabled person and the labour office. Employers are obliged to contact the relevant authorities if a severely disabled person applies for a job or if problems arise with his or her employment. They are also required to formulate integration agreements with the authorities, containing 'concrete statements' about personnel planning, workplace layout, labour organisation and working time. The rights to be consulted enjoyed by responsible representatives at the workplace (*Vertrauenpersonen*) have also been extended.

# Rehabilitation and extended employment measures

This section refers to rehabilitation provisions of the BA. Rehabilitation may also be organised through other channels.

### Decisions to be made, criteria

The Social Code Book III obliges the BA to take account of the 'personal circumstances' of those it supports when providing benefits or services. These may include health problems which limit a person's occupational choice. Medical reports may be sought for a variety of reasons, e.g. determining whether a person had good cause to leave the previous job due to ill-health. The medical service acts only on the instigation of another BA service (e.g. occupational guidance, vocational guidance, benefits).

Limitations in performance in a specific job (or proposed occupation or rehabilitation and training plan)

The medical report 'serves to determine individual capabilities and to provide the employment office in this way with an objective foundation for its efforts at placement or support, or for decisions on financial benefits'. (BA, 'The Medical Service of the BA', July 1999 (in English)). Whether 'threshold' decisions about the extent of a person's incapacity arise depends on the individual case, e.g. if availability for work is limited (see above incentives and requirements). Generally, the Medical Service advises on the appropriateness of certain occupational choices and training and rehabilitation options.

More generally, the assessments are always on the subject of 'occupational disability' in that they consider the obstacles a person faces in obtaining work.

### Personnel

The Medical Service of the BA employs its own doctors and also has contracted panel doctors. Panel doctors may be contracted from a variety of areas, including the social insurance institutions. There is an emphasis on the 'objective determination' of health problems.

Some enquiries from BA services can be answered using medical records; a medical examination is not always conducted. If necessary, specialist reports can be commissioned.

#### Rules and instruments

The BA Medical Service uses forms and rubrics which are very similar to those used by the Pension Institutes in the administration of EMR (see Appendix 1). In particular, the medical report provides a 'positive image' (what the person is capable of) and a negative image (what employment must be excluded). This image is then compared with the specific employment being considered, in order to determine whether it is suitable.

### Observation in context

The medical report is done on the instigation of another service in relation to a specific proposal, e.g. for vocational training.

Rehabilitation plans may be developed with the aid of information derived from speciallyequipped testing facilities. For example, the ERGOS pilot project involves a very detailed assessment for the purposes of designing an individual's rehabilitation programme.

## Role of disabled person

The consent of the person is required for a medical report to be done. The rehabilitation plan (*Reha-Gesamtplan*) is discussed with the person.

Role of employer(s)

Not involved.

#### **GREECE**

### **Provisions**

The employment provisions discussed in the national report are the quota system and system of employment subsidies for persons with special needs.

The quota system also applies to other groups of people seen as especially deserving of an advantage in obtaining (an income from) employment. These include war invalids, members of the family of a disabled person as well as parents in families with many children, ex-members of the national resistance, etc. The 'global' quota is 8%, of which 2% is for people with special needs (3% in the public sector).

The public sector also retains some job reservation rules, e.g. a certain proportion of telephonists' jobs must go to blind people.

## Institutional responsibilities and linkages

The certification of a person's disability rate rests with the Health Committees of IKA and the Ministry of Health and Social Care.

To be eligible for the quota or subsidies, the person also has to be registered as unemployed with the Employment Office (OAED). The OAED administers the quota by assigning the workers with the most points to job vacancies as they arise.

Linkages to mainstream ES measures and measures for other groups with labour market disadvantages - The Greek employment service has received considerable funding from the European Social Fund (ESF), some of which can potentially be directed to people with disabilities. However, Greece has not elected to incorporate e.g. vocational assistance to disabled people in its use of ESF funds.

## Incentives and requirements to participate in measures

The definition of disability for the quota is the same as is used for IKA pensions and for the disability card. However, receipt of an IKA pension does not mean that a person has an advantage obtaining employment under the quota. On the contrary, the provisions favouring those with a low income, along with rules on abating the pension with earnings, mean that the quota is largely directed to those who are not eligible for a pension.

#### Assessments

## Decision to be made, criteria

To be eligible for measures, the person have a disability rate of 50%+. In determining the number of quota points a person receives, the following additional criteria are considered by the OAED:

- age of the candidate
- professional qualifications
- family circumstances
- economic (financial) situation.

For the quota, the age range is 21-45 years old; for subsidies it is 18-65.

## Personnel

The Health Committees are made up of doctors.

## Rules and instruments

The Guide for the Evaluation of the Disability Rate (see Appendix 1) is applied to determine the disability rate.

## Observation in context

none generally, but see under 'role of employers'.

## Role of disabled person

The disabled person must take the initiative of registering with OAED.

## Role of employer(s)

In principle, employers are bound by a rigorous system of job nomination. However, employers can seek medical certification that the nominated person is not suitable for the job. The assessment of suitability is subject to the obligation on the employer to adapt the workplace, if the cost of adaptation is not excessive. Employers may also seek replacement of the candidate after a two month trial period.

#### **IRELAND**

#### **Provisions**

A variety of employment related supports to help people with disabilities gain or retain employment are available through the national training and employment authority, FÁS. These include:

- Job Interview Interpreter Grant for job seekers who have a hearing or speech impairment and are attending job interviews to have an interpreter attend the interview;
- Personal Reader Grant for blind or visually impaired people who need assistance with job related reading, to employ a personal reader. The grant is available for up to 16 weeks;
- Employment Support Scheme (ESS) which offers financial assistance to employers to encourage them to employ people with disabilities whose work productivity levels are between 50-80% of usual performance;
- Workplace Equipment/Adaptation Grant (WEAG) which contributes to any additional costs to an employer in employing or retaining an employee with a disability, provided the additional costs relate to the disability;
- Grant to Retrain Workers who become Disabled while in Employment to assist employers to retain at work employees who become disabled through sickness or injury;
- Supported Employment Programme under which people with disabilities who need additional assistance are helped to get and retain employment through the provision of Job Coaches:
- Disability Awareness Training Support Scheme which aims 'to assist in the integration of people with disabilities into the workforce and to eliminate mistaken perceptions about people with disabilities and their capacity to be productive and effective colleagues and employees' through the provision of training grants;
- Training Allowance for People with Disabilities: before mid-2001, people with disabilities on training programmes relied on social welfare benefits, and there was no allowance for those who were not eligible for social welfare. The change in 2001 was intended to ensure that the same rights and benefits were available to all.

People with disabilities can access two types of training: - Rehabilitative Training which is provided by Health Boards or by specialist agencies on their behalf and Vocational Training which is provided by FÁS or by specialist agencies under contract with FÁS.

Disabled people may also participate in the Community Employment programme (through FÁS). Generally the lower age limit for the CE programme is 25 but the age limit for people with a disability and Travellers is 18 years or over.

# Public Service Quota

3% of jobs in the public sector (civil service, local authorities, Health Boards) are reserved for people with a disability.

## Institutional responsibilities and linkages

There have been significant institutional reforms in Ireland as a consequence of the recommendations about 'mainstreaming' services in the report of the Commission on the Status of People with Disabilities ('A Strategy for Equality', 1996).

In March 2000 the National Rehabilitation Board was abolished and its vocational training and employment service activities 'mainstreamed' into FÁS, the national training and employment authority, which comes under the Department of Enterprise, Trade and Employment. (Other activities were transferred to other mainstream bodies, particularly the health boards.) The National Disability Authority and Comhairle were established at the same time. The NDA is charged with bringing a disability perspective to the work of all government departments and state agencies. Comhairle is an information and advice service; it has a 'mainstream' remit of providing information for all citizens. Provision of information to people with disabilities is a significant part of its work.

Private and voluntary organisations are the main providers of specialist disability services. The supported employment programme operates through a range of organisations

There has been a renewed drive to comply with the 3% quota in the public sector, with the establishment of a monitoring committee in 1997 and increased trade union advocacy of compliance.

## Incentives and requirements to participate in measures

No compulsory participation

#### Assessments

Decision to be made, criteria:

No specific definitions of disability. There is some suggestion that people with minor disabilities are included in the 3% quota in the public sector. Questions about how disability should be determined by FÁS are also unresolved. The NRB used to supply services to disabled people who were referred through specific channels – these entry routes constituted the de facto process of defining disability. With institutional reform, the definition of disability has become an open question. The wide definition of disability adopted in the Employment Equality Act (see chapter 5) is recognised as having implications for FÁS.

#### Personnel

FÁS officials decide where to refer the person

#### Rules and instruments

Receipt of social security benefits or referral from education system often used to indicate disability.

## Observation in context

Providers of supported employment may assess the suitability of a person in a trial period.

## Role of disabled person

Not explicitly set out.

## Role of employer(s)

Attempts to involve employers more, e.g. through Disability Awareness Campaign

## **ITALY**

#### **Provisions**

The employment provisions discussed in the national report are those arising from the 1999 Act which reformed the system of 'directed placement' (*collocamento mirato*). The Act reduced the quota rate (from 15% to 7%) but strengthened its enforcement by providing penalties for non-compliance. Exemptions from social contributions were introduced for employers taking on more severely disabled workers, and provision was made for financial support for workplace adaptations.

Some provincial governments have extended measures further by providing extended vocational guidance, support workers and job coaching as part of their administration of the collocamento mirato for disabled people.

## Institutional responsibilities and linkages

The implementation of the 1999 Act is the responsibility of provincial governments, specifically the tripartite *Commissione provinciale per le politiche del lavoro*. The provincial employment service (*servici all'impiego*) maintains the register of the unemployed disabled. The first steps to qualification as disabled for the purposes of the quota are 'passported' (see below).

Linkages to mainstream ES measures and measures for other groups with labour market disadvantages - no linkages.

## Incentives and requirements to participate in measures

No requirements connected with the cash benefit system.

#### **Assessments**

Act 68/1999 emphasises that the process of assisting the client should focus on the person's 'residual working capacity' (the positive capacity) rather than establishing their reduction in working capacity.

# Decision to be made, criteria

Five main groups of disabled people can qualify for the quota:

- civil invalids (with a certificate *di invalidita del lavoratore*) with 45% or less remaining capacity. Civil invalidity (which is relevant also for non-insurance based benefits) is assessed by medical panels set up in conjunction with the health service.
- work invalids (*invaliditi del lavoro*, as assessed by INPS) with 33% or less remaining capacity
- deaf-mutes and blind (for whom provision generally is covered by separate legal provisions)
- invalids of war.

These four groups are subject to the process of drawing up a detailed profile, as explained below, before they are registered.

- people disabled as a result of work injury or occupational disease (assessed by INAIL) are registered without any further process of detailed profiling.

A person who meets one of the above conditions and wishes to obtain employment is further assessed by a Technical Committee which prepares a Working and Social Profile (WSP).

#### Personnel

The initial determination of disability is done by doctors. The technical committee is composed of doctors, social workers, employers' and employees' representatives, local and regional government representatives, labour market experts, and experts in disability care and rehabilitation.

#### Rules and instruments

The medical panels apply WHO norms and concepts, in accordance with Decree no 509, 1988 of the Ministry of Health (discussed further under care service provisions). The medical panel provides the Technical Committee with a Functional Diagnosis, in accordance with the Decree of Jan 2000 which sets out the parameters.

The WSP prepared by the technical committee includes information on the person's:

- qualifications
- work competences
- types of work that might be suitable
- nature and degree of disability.

## Observation in context

The intention of the reforms was that a disabled person's competences would be carefully considered in order to place him or her in a suitable job: 'the right person for the right job'. In practice, the WSP can be done abstractly or in close conjunction with possible employers, depending on the provincial office.

## Role of disabled person

No information available.

## Role of employer(s)

The counterpart of the strengthened enforcement of the quota since 1999 is that employers have more input into the placement process, in line with the general reforms in the labour market which took place in the 1990s.

#### **NETHERLANDS**

#### **Provisions**

The national report discusses the provisions under the Work Handicapped Reintegration Act (REA). There is a separate process of allocation of places under the Sheltered Workshop Provision Act (WSW).

REA provides a general frame for increasing the labour market participation of people with a 'work handicap'. It places the general responsibility for integrating disabled people on employers and unions. Its predecessor, WAGW (1987) used the threat of a quota as the lever to get the social partners to take measures. This was ineffective. REA introduces some financial incentives, including:

- employers are offered a fixed budget for every disabled person they take on (in principle to finance adaptations, although the actual cost of adaptations can be less than the budget);
- sick pay for disabled people is met from the national sickness fund, rather than by the employer:
- WAO contributions are reduced if 5%+ of the payroll is to people with disabilities;
- a personal budget has been introduced for disabled people entering employment.

## Institutional responsibilities and linkages

For those not in one of the groups passported into REA eligibility (see below), the institutions which assess the handicap can be:

- the municipality in the case of social assistance claimants:
- Administrative bodies (uvis) of the National Institute for Social Insurance (LISV) for those receiving unemployment insurance, and for employees;
- The Labour Office for registered unemployed without benefits, and employees, although in practice they delegate assessment to the uvis.

WSW places are allocated by municipal selection committees. A waiting list is maintained and places are allocated to the highest listed person with matching capacities.

A large number of people are partially disabled, and this means that they have some contact with the mainstream unemployment system (for that 'part' of their capacity to work). Measures for the long-term unemployed may be important to the partially-disabled. There is a variety of measures under general employment-promotion measures (WIW) for the insertion of job-seekers, particularly through job creation by the municipalities. Since 1998 WIW is not restricted by group (young, long-term unemployed etc).

## Incentives and requirements to participate in measures

The preamble to REA stresses equity as the reason for promoting reintegration, but the real motive for the measures would seem to be to get people off disability benefits, as is indicated by the close links between WAO and REA assessment.

## Assessment (REA)

## Decision to be made/ criteria

The Resolution on the Work Handicapped (1998) sets out four questions:

- is there an illness or infirmity that leads to structural functional limitations (physical, mental)?
- is there a risk of serious health problems in the next five years?
- do the limitations have as a consequence that the person cannot work more than 75% of a normal working week?
- are REA-measures necessary in order to enable the person to perform work functions normally?

The Resolution contains a schema of steps to be taken when assessing the points mentioned.

Many people derive eligibility for REA from their eligibility under other measures (passporting). These include:

- 1. recipients of a disability benefit (WAO, Waz or Wajong);
- 2. people using a provision aimed at maintaining or recovering work capacity (e.g. a WVG mobility provision like a wheelchair);
- 3. people with a WSW-indication, but who do not have a WSW-job (there is a WSW waiting list because of too few places being available);
- 4. people whose disability benefit (WAO, Waz or Wajong) terminated no longer than five years ago.

#### Personnel

When assessment is done by the uvi (as for WAO), both insurance physicians and labour market experts are involved.

#### Rules and instruments

There are no standardised instruments for REA as such, but there are for the 'passporting' benefits (e.g. WAO uses a 'capacity profile' (see Appendix 1 for details)). The Resolution on assessment acknowledges variations in assessment practices, and says that it is assumed that institutions and experts will follow closely the standard practices used in the assessment of WAO claims (in cases where the REA assessment is done by the uvi and Labour Office), and WSW and WVG claims (in cases where the REA assessment is done by the municipality).

#### Observation in context

There is an element of assessment in context arising from the need to obtain a job offer before REA measures become relevant.

## Role of disabled person

The disabled person's 'proactivity' is central to REA, as the measures must be accompanied by the person obtaining a job.

# Role of employer(s)

Where an REA subsidy is being sought, the employer may initiate the application.

## **NORWAY**

#### **Provisions**

Provisions for the promotion of employment of disabled people are found in a number of different legal acts. The most important are the Working Environment Act (WEA), the Planning and Building Act, the National Insurance Act and the Employment Act.

The national report focuses mainly on the WEA. It is a general act and not concerned exclusively with the employment of disabled people. The act gives employers an obligation to provide access to the workplace for the 'vocationally disabled' (*yrkeshemmede*) and reasonable accommodation for people who have become disabled while employed in the enterprise (Section 13). The act also makes it illegal for employers to discriminate against job applicants on the grounds of disability. The non-discrimination provisions are discussed in chapter 5 of the main report.

## Institutional responsibilities and linkages

The Local Labour Inspectorate (*Det lokale arbeidstilsynet*) has the general responsibility for supervising compliance with the WEA.

# Incentives and requirements to participate in measures

Not applicable

#### Assessments

## Decision to be made, criteria:

What is meant by the term a 'vocationally disabled' employee (*yrkeshemmet arbeidstaker*) is not defined in the WEA or binding regulations made under this Act. However, the guidance to the Act - issued by the Directorate of Labour Inspection - provides some suggestions: "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 ageing, etc. The WEA is general and regulates all conditions that affect the physical, psychological or social sides of the work environment. This applies to all employees in the enterprise, including those who have such problems as mentioned and whom in this context are called vocationally impaired". Moreover, the guidance makes it clear that physical impairments as well as mental, social and complex problems may be associated with vocational disability.

In regulations under the Employment Act (*Sysselsettingsloven*) on labour market measures, vocationally disabled persons are defined as 'persons who have had their earning capacity diminished, or their possibilities for choosing occupation or workplace reduced substantially. The cause for this may either be illness, injury or defect, or social maladjustment.

The National Insurance Act tends towards a narrower definition of disability: 'social problems', 'effects of drudgery and ageing' are not disabilities under the NIA.

#### Personnel

Under the WEA, the key role is played by the labour inspector. In larger enterprises with health and safety personnel, these are likely to be involved in the assessment of the need for job adjustments or transfer. Enterprises with more than 50 employees are obligated to set up a special Work Environment Committee (*Arbeidsmiljøutvalg*) (ibid. Sections 23-24). Members of these bodies are trained to deal with work environment issues and are also to be involved in issues related to the accommodation and job transfer for employees who become vocationally disabled. Individual employees can present claims, complaints or requests through their union representative (shop steward), the Safety Deputy or the Work Environment Committee, or they can address the questions directly to the manager of the enterprise.

#### Rules and instruments

The guidance to the WEA does not give any guidelines or recommendations about how the degree or nature of the diminished capacity for work is to be assessed in the enterprise. Rather it emphasises that the basis for organisational arrangements and technical adjustments in the workplace must be the situation and abilities of each individual employee, seen in relation to the demands of his or her work. In practice assessments of the employee's capacity and abilities that are available under other legal provisions, e.g. the sickness and rehabilitation benefits under the National Insurance Act (Folketrygdloven) are probably often used.

#### Observation in context

All measures under the WEA imply observation in context.

## Role of disabled person

The law leaves a scope for negotiations about personal and social circumstances that may affect the work ability of an employee. Generally speaking, it is up to the employee to claim that he or she has become vocationally disabled and in need for accommodation, special on-the-job arrangements or a job transfer.

# Role of employer(s)

The WEA is a regulatory measure which imposes far-reaching responsibilities on employers.

## **PORTUGAL**

#### **Provisions**

A wide range of schemes has been introduced in Portugal to promote the employment of people with disabilities. They include:

- Support for the social and vocational integration of disabled persons (*Apoios à integração socioprofissional de pessoas deficientes*). This support comprises financial assistance for enterprises for:
  - \* recruitment of disabled persons on open-ended employment contracts or conversion of fixed contracts to open-ended ones;
  - \* recruitment of disabled persons with a reduced capacity to work. Aid is provided in the form of financial compensation for the period of adaptation or readaptation for a maximum duration of four years;

- \* elimination of architectural obstacles when adapting buildings to the functional needs of disabled workers;
- \* recruitment of disabled persons who require individual supervision and assistance during the integration period.
- Sheltered employment scheme (*Programa sobre emprego protegido*) provides permanent and paid employment, including on-the-job training and, if possible, transition towards regular employment.
- Integration enterprises (*Empresas de inserção*) which aim to combat poverty and social exclusion through vocational (re)integration measures, support in the acquisition and development of the personal, social and vocational skills required for engaging in paid employment, and job creation to fulfil needs which are not met by the regular labour market. Thus these enterprises are not specifically for disabled people.
- Other specialised training and rehabilitation programmes (Rehabilitação Profissional).

# Institutional responsibilities and linkages

The Institute for Employment and Training (*Instituto do Emprego e Formação Profissional* (IEFP)) administers schemes through *Centros de Emprego* (job centres) and specialised rehabilitation institutions.

## Incentives and requirements to participate in measures

No information available.

#### Assessments

Decision to be made, criteria

Measures administered through *Centros de Emprego* are open to people with disabilities, independently of the nature and degree of the disability.

The sheltered employment scheme is open to disabled persons of legal working age who, due to their handicap, cannot be directly integrated into the regular labour market.

For ongoing (up to 4 years) financial subsidies, the disabled person must have a reduced capacity to work.

# Personnel

Officials of the IEFP make the decisions.

#### Rules and instruments

In principle, the National List of Incapacity (see Appendix 1) could be used.

## Observation in context

Subsidies under the provisions on financial subsidies are negotiated on a case-by-case basis.

Role of disabled person

No information available.

Role of employer(s)

Employers' proactivity is promoted through e.g. the *prémio de mérito* scheme, a symbolic recognition of enterprises which are active in promoting the employment of people with disabilities.

## **SPAIN**

#### **Provisions**

A quota for the employment of handicapped workers is in force, obliging employers with a permanent workforce of over 50 people to set aside 2% of posts for handicapped workers (Real Decreto 27/2000, of 14 of January, (B.O.E. núm. 22 of 26-01-2000)). The quota has recently been reduced, but its enforcement enhanced with the requirement that employers who do not comply must make contributions to organisations that provide employment or training for disabled people, or source goods or services from Special Employment Services.

Firms taking on handicapped workers are eligible for incentives taking the form of social security contribution relief. Subsidies and tax/contribution relief is granted to schemes involving the creation by firms of sheltered employment centres for handicapped workers.

# Institutional responsibilities and linkages

Quota reforms followed from an agreement between the Ministry of Work and Social Affairs (*Trabajo y Asuntos Sociales*, MTAS) and the Spanish Committee of Representatives of Disabled People (CERMI).

A great variety of institutions is involved in the provision of sheltered workshops (*Centros Especiales de Empleo*), rehabilitation centres and employment services. Social services departments of the independent communities co-ordinate these provisions.

# Incentives and requirements to participate in measures

People may obtain an assessment of their degree of handicap in order to access a variety of measures including non-contributory social security benefits.

## Assessments

Decision to be made, criteria

Eligibility for the quota requires a degree of handicap of 33%+. A general classification of disability is used; there are no special provisions relating to work limitations or other specific aspects of disability affecting employment.

Spain has a data base of people with disabilities (*La Base de Datos Estatal de Personas con Discapacidad*) which aims to provide information for all the institutions which have a disability-related remit and to include all those recognised as having a certain degree of disability by the competent administrative agencies of the State.

#### Personnel

Assessments are by multi-disciplinary teams.

#### Rules and instruments

The assessment utilises the scheme contained in the Guide *Valoración de las situaciones de minusvalía* (VM).

#### Observation in context

Not applicable to the general assessment of degree of handicap.

Role of disabled person

Not applicable.

Role of employer(s)

No role in determining the person's degree of disability.

#### **SWEDEN**

#### **Provisions**

The employment provisions discussed in the national report are:

Social insurance provisions:

- 1. Rehabilitation benefit and services
- 2. Work aids and facilities working aids handled by the social insurance office are given to the individual as part of the rehabilitation process, cf. AMS measures payable to the employer (below).
- 3. Handicap allowance

Labour Market Board (AMS) provisions:

Special adaptations and subsidies for disabled job-seekers provided through AMS include:

- Financial support for working aids at the workplace financial support to person who bears the cost (e.g. employer).
- Special measures for persons with visual and hearing impairments, including training of personal assistants, transfer of materials into Braille, etc.
- Support for personal assistance provides economic support to an employer or other person, having to bear costs for a personal assistant to a work-related disabled person in need of such an assistance in his/her role as an employee, self-employed, etc.
- Supported employment The regional labour market board appoints a special support-person for a person with work-related disability in need of extra training and support in the initial phase of an employment period.

- Subsidised employment: Subsidies may be given to an employer of a disabled person if this support is needed in order for the person to gain or keep a job. The time-period for subsidised employment must normally not exceed four years.
- Sheltered employment, either a) Employment at the Samhall company or any of its affiliated companies; or b) Employment with a public employer (state, county council or municipality).

Where an employer receives financial help (grants for adaptation, subsidies) to take on a disabled worker, that worker is regarded as employed under a 'special contract' and has extra protection against dismissal under the Employment Protection Act.

Work Environment Act: The general administration of this Act is done by the Work Environment Authority (www.av.se). Measures under this Act may benefit disabled people (see the discussion in chapter 5 of the main report).

## Institutional responsibilities/linkages

As can be seen, there is some overlap between the responsibilities of the social insurance office and the public employment office (PEO). Furthermore, municipalities provide social assistance and special municipality jobs and other provisions for the hard-to-employ, which may include e.g. persons with socio-medico disabilities (alcoholics, drug addicts), persons covered by LSS, or long-term unemployed persons with severe psychiatric problems.

The Swedish report analyses the different perspectives of the institutions involved as follows. '[T]he social insurance office's conception of work capacity is individual, i.e., related to the health status (as it is described in the medical certificate), the outcome of functional and work tests and the aspirations of the individual. However, the labour market authorities typically look at this issue from an employability perspective, which means that they consider the real chances of getting a job. Labour market authorities often demand that the person is "ready made" for entering the labour market, i.e., healthy and motivated (which is often not the case for an unemployed sick-listed person).' (Swedish report, p.17)

If the PEO considers a person to be unemployable, he or she may be referred back to the social insurance office. However, if there is an insufficient objective medical basis for social insurance benefits (see Appendix 1), the person may have to apply to the municipal social welfare office for assistance and services. The report describes the potential for the person to be '(endlessly) circulated between welfare agencies' (Swedish report, p.18).

# Incentives and requirements to participate in measures

The 'step-by-step' process for the award of disability benefits involves consideration of the possibilities for rehabilitation and a return to work, possibly aided by one of the social insurance measures noted above. Social security offices have a very flexible mandate as regard the specific vocational rehabilitation measures in each case. The benefits noted above provides income maintenance but the content of the rehabilitation activities can vary: training in the former workplace, in another workplace, vocational education etc. The benefits are just the skeleton/framework to be filled up with other activities. Employers have certain duties in respect of their sick workers which may increase their interest in taking up the measures listed.

A person registered as unemployed with the PEO, who declines to take up measures offered to assist him or her into work, risks being designated unemployable and circulated to the social welfare office, as described above.

#### **Assessments**

# Handicap allowance

#### Decision to be made

The functional capacity of the person must "for a considerable time-period have been reduced to the extent that the person .. b) in order to be in gainful employment needs continuous help from another person.. ". Being a student (receiving public educational support) is here equated with being in gainful employment.

[Note that this allowance is also available for a person who a) in his/her daily activities needs time-consuming help from another person; or c) has considerable extra living costs. Here we discuss the help provided for maintaining gainful employment.]

However, diagnosis/ impairment does not bring entitlement.

#### Personnel

Normally a medical certificate is needed, but doctors do not play an important role. The key actors are the personnel from the social insurance office.

#### Rules and instruments

The blind or deaf (or persons with severe hearing impairments) are always entitled to handicap allowance.

## Observation in context

The emphasis is very much on observation in real-life situations. The National Social Security Board recommends that the social insurance office collect information concerning: the employer, the work tasks, working time, the kind of help the disabled person needed to transport him/herself to the work place, travel mode and travel time, the need for help in order to perform (part of) the work tasks and the time that takes and the frequency of the help, the need for help in order to move around in the work place, information on who gives the help and whether that person receives remuneration from other than the disabled, how much such help for the disabled person costs.

## Role of disabled person

Consent required.

## Role of employer(s)

Employers do not have specified duties to contribute towards the costs covered by the Handicap Allowance. However, they do have duties in the area of rehabilitation (to contribute to the rehabilitation costs of their own employees) and related obligations under the Law prohibiting discrimination against disabled people in employment. The report notes that 'social insurance officials often end up in arduous negotiations with employers who will not or cannot meet expectations of taking care of their own long-term sick employees' (Swedish report, p.17).

#### **Labour Market Service Measures**

#### Decision to be made/ criteria

The definition of disability that applies for all the measures is that "a person with a work-related disability is a person who due to functional limitation has reduced work capacity and therefore has, or can be expected to have, difficulties in gaining or keeping regular employment".

The person must be registered with the Public Employment Office (PEO). If s/he is assessed to be not immediately employable the PEO-officer may suggest a functional or work test at a Labour Market Institute (from 2001 called *AF-Rehabilitering*, a special unit within the labour market administration). Most disabled job-seekers are transferred to these institutes.

#### Personnel

The decision is made by the PEO officer who has considerable discretion.

#### Rules and instruments

The person is classified by the PEO-officer as a disabled person by means of a list of handicap categories (*handikappkoder*). These categories are a mixture of diagnostic (e.g. cardio-vascular and/or lung disease) and impairment-oriented (e.g. mobility-impaired, wheelchair user) items.

AF-Rehabilitering offer a variety of work tests, psychological aptitude tests and practical training. However these rehabilitation instruments are not primarily directed towards establishing a threshold for judging a person to be disabled.

Despite these formal disability-related categories and instruments, the report suggests that the boundary between disability and low employability is fluid. A report from the Swedish National Audit Office has suggested that PEOs are increasingly classifying the hard-to-employ as occupationally disabled (Swedish report, p.18). This classification makes them eligible for employment subsidies and for places at Samhall.

# Observation in context

Rehabilitation processes allow for a certain amount of observation in context.

# Role of disabled person

The disabled person must always approve the classification that is done.

Role of employer(s)

None.

#### **UNITED KINGDOM**

#### **Provisions**

The employment provisions noted in the national report include a variety of schemes administered through Disability Employment Advisers (DEAs) in Employment Service offices (Jobcentres; now Jobcentre Plus offices (see below)). Some schemes, particularly the New Deal for Disabled People (NDDP) may also be accessed through New Deal job brokers (also based in Jobcentre Plus offices). The provisions include:

- Employment assessment and advice on training, placement etc.
- Job introduction scheme, which pays a weekly grant for a short period (6 weeks) to employers trying out a disabled person in a new job;
- New Deal for Disabled People (NDDP), which consists of a variety of 'innovative schemes' for job matching, advice and support when a person starts work, run by various agencies under contract to the Employment Service;
- Work preparation, which is similar to the New Deal schemes;
- Residential training, specifically for disabled people;
- Work-based learning for adults, which is also available to long-term unemployed people;
- Workstep, which is a supported employment programme. Disabled people are employed either in mainstream jobs or supported factories. The employee is paid the rate for the job and the provider receives a subsidy. (The provider may be an employer, but often it is an intermediary such as a voluntary organisation or local authority, which supports disabled people in mainstream employment. The employer is not necessarily subsidised.)

For people who are already in work, or have a job offer, the Access to Work (AtW) scheme pays for communicators, support workers, fares to work, specialist equipment and adaptations to premises. It is administered by AtW advisers.

An income top-up is available to disabled people in employment. It now takes the form of a tax credit: the Disabled Person's Tax Credit (DPTC).

## Institutional responsibilities and linkages

The government has taken a number of steps to increase the linkages between the provision of employment services (in Jobcentres) and the process of claiming for social security benefits (in Benefit Agency offices). In April 2002 the offices of the Employment Service and the Benefit Agency were merged with the creation of Jobcentre Plus offices.

A recent innovation is for the Approved Doctor who assesses a person for Incapacity Benefit (see Appendix 1) to provide a Capability Report, which identifies the work-related activities a person can manage despite their disability. The findings of the Capability Report do not (at present) affect the determination of disability for Incapacity Benefit purposes.

A number of agencies provide services for disabled people, under contract to the Employment Service. These contracts generally specify performance targets which may tend to mean that providers favour less-disabled workers. For example, providers of supported employment places under Workstep have targets for progression to non-supported employment and the policy is that levels of subsidy for their workers should decline as the supported placement period lengthens.

## Incentives and requirements to participate in measures

None of the provisions administered through DEAs is linked to qualification for benefits.

Traditionally, a person receiving IB could not work without this raising questions about whether he or she is sufficiently incapacitated to continue to qualify for the benefit. However, there are some exempt and approved categories, and the scope of 'permitted work' has recently been extended.

Furthermore, the NDDP, the establishment of JobCentre Plus offices and the introduction of the Capability Report all seek to change the traditional pattern of excluding IB recipients from employment programmes. It is not necessary for a disabled person to leave IB and claim Job Seekers Allowance (which has lower rates) in order to obtain access to NDDP. In addition, claimants who live in an area where work-focused interviews are in place (a ONE pilot area) must attend their interview or face the possibility of disqualification from benefit.

The DPTC is intended to provide a route into employment for people receiving out-of-work disability benefits, as indicated by the 'passporting' provisions which enable benefit recipients to qualify automatically for DPTC.

#### Assessments

## Workstep

Decisions to be made, criteria

There are two main criteria:

- the person must satisfy the Disability Discrimination Act (DDA) definition of disability: having a physical or mental impairment which has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities;
- the person must have been on benefit for six months previously, or be in work and in danger of losing his or her job, or be an education leaver with clear evidence of the need for support in work.

Before April 2001, the first criterion was that the person could not get or retain a job in open employment, and that his or her productivity was between 30% and 80% of normal productivity.

#### Personnel

The DEA certifies that the DDA definition is satisfied and that one of the other eligibility conditions is met. Evidence from the person's doctor may be obtained in cases of doubt.

#### Rules and instruments

Guidance on the DDA definition is available to the DEA.

## Observation in context

Technically, the assessment is not based on observation in context. In practice, however, the process of determining eligibility may begin with finding a suitable placement, after which the criteria can be checked off.

## Role of disabled person

Under the revised scheme, there is more emphasis on tailoring provision to the employee's needs, and job coaching and advice is provided to the disabled person.

## Role of employer(s)

Since April 2001, providers of Workstep places (as noted above, these may be intermediary organisations or employers) are subject to more stringent targets on progression to non-supported employment than they were previously. It appears to be envisaged that these targets will be met by greater awareness and more proactivity on the part of providers, to identify the disabled person's strengths and develop his or her employment potential.

## **Disabled Persons Tax Credit**

## Decisions to be made, criteria

There are two main sets of criteria:

For a new claim, the person must be receiving, or have recently received, any of a number of qualifying social security benefits ('passporting');

For continuation of a claim, passporting is also relied on, particularly from care and mobility benefits (e.g. higher rates of Disability Living Allowance). In the absence of passported eligibility, a 'disability test' may be applied.

#### Personnel

Clerical officers check the passporting conditions, and also make the decision on the 'disability test' using information obtained from the applicant's own doctor. Use of SEMA (the medical services which conduct investigations for the main social security benefits) is possible but rare.

#### Rules and instruments

A Decision Makers Guide sets out the passporting conditions and the components of the disability test. If the latter applies, one of 21 conditions must be satisfied, relating to e.g. inability to stand, walk, use the arms or hands; limitations to eyesight, hearing, clarity of speech, consciousness; inability to work a full 40-hour week etc. The conditions are similar to those in the Personal Capacity Assessment (PCA) used in Incapacity Benefit administration (see WP1); however, the level of incapacity required is much lower for DPTC as only one condition needs to be satisfied (cf. the accumulation of points in the PCA).

The Guide specifies the application of the test in great detail, e.g. what is meant by 'walking'.

## Observation in context

None, but note circumstances under which disability is evaluated with reference to specific employment conditions (see below under role of employer).

# Role of disabled person

The person must apply for the benefit.

# Role of employer(s)

The test of whether a person cannot sustain a working week revolves around the issue of whether the employer has made special concessions to the person. A person who claims to be exhausted by a normal working week will not qualify if he or she continues to work a normal week without adaptation by the employer. Where the employer allows additional rest periods, avoidance of certain tasks or special breaks, the test is deemed to be satisfied (Decision Makers Guide DMG13040).

# Appendix 3 Definitions in assistance with activities of daily life and promotion of independent living

Provisions to assist people who need help, or incur extra costs, in performing activities of daily life in the Member States include long-term care provision, cash benefit provisions for transport costs, special diets and other needs, and concessions for disabled people such as free or discounted use of public transport, discounts on other utilities (TV licences, telephone charges, etc) and tax concessions. The country-by-country summaries set out contextual information under the following headings:

#### **Provisions**

Institutional Responsibilities

#### Nature of needs met

(medical care, personal care, home help, mobility, social contact, extra consumption expenses)

## Nature of provision

(whether services are provided or cash; if cash, standard amounts, reimbursement for actual expenditure; if services, extent to which individual entitlements are specified)

Linkages with other definitions of disability

Age limits

Means- and resources-testing, co-payment.

## Assessment processes are described as follows:

# General definition:

Here we have noted the general description of disability related to the provision, if any is given. Some descriptions specify that a person's needs must be the consequence of an abnormal condition, while others do not. For example, the general description in Austrian care insurance is that eligibility depends on.. 'the permanent need for support and care as a consequence of a physical, mental or emotional or sensory disability..' whereas the Swedish LSS description is that a disabled person is a person with 'large and persistent difficulties in managing daily life'.

#### Specified impairments:

Here we note whether groups with particular impairments are specifically mentioned as eligible and/or have their own special provisions. Impairments may be specified for historical reasons and may also be used as an administrative shortcut, reducing the requirements for detailed assessments.

## Personnel:

The personnel involved may be doctors, nurses, social workers, multi-disciplinary teams or administrative officers of the social security system.

## Rules and instruments:

## Observation in context:

This gives us some insight into the extent to which disability is seen as being contingent on particular social and environmental conditions.

# Role of the disabled person:

This heading is most relevant to provisions in kind or non-fungible cash payments, where some states have adopted measures to empower the disabled person to define his or her own needs and/or to have a voice in how needs are met. For example, some states enable the disabled person to choose to be the employer of a carer, rather than accepting care services provided by an institution which employs the carer.

All information relates to 2001, when the national reports were being written. Where applicable, changes introduced before 1 Jan 2002 are noted.

#### **AUSTRIA**

#### **Provisions**

The main independent living provision discussed in the national report is the Federal Attendance Allowance Act (BPGG) (1993). This Act partly replaced existing provisions under Provincial social aid legislation, but the old Provincial measures also remain in force.

## Institutional Responsibilities

The BPGG provides for attendance allowances for pension recipients (mainly old age and disability pensions). In addition to the BPGG, nine corresponding Provincial Acts were passed, which provide attendance allowances (on the same basis) for those whose main source of income is supplementary benefits, people who are working, etc.

For pensioners, their pension institution is responsible for administering the allowances. Payments are reimbursed from central government revenue. Non-pensioner payments are administered by the provinces but centrally financed.

#### Nature of needs met

Personal care (*Betreuung*) and support (*Hilfe*) are distinguished. Personal care includes personal hygiene and washing, preparation and eating of meals, taking medicines and help with mobility 'in the narrow sense', e.g. getting up and going to bed. Support includes bringing in food and drugs, domestic cleaning, laundry, other domestic tasks and help with mobility 'in the broader sense'.

## Nature of provision

The Allowance is paid in cash. There are seven levels defined according to the number of hours of care needed per month (level 1: 50 hours, level 4: 160 hours) and the intensity of care and severity of the person's condition (levels 5-7, all involving at least 180 hours of care).

# Linkages with other definitions of disability

As noted above under 'Institutional Responsibilities', the delivery of allowances is done by the pension insurance institution for pension recipients, and otherwise by the social offices of the provincial government. If a person's income and/or employment status changes, there may be a transfer of institutional responsibility, in which case there will be a new assessment. For example, a recent controversy over the case of Andrea Mielke arose when she was unable to continue part-time work and qualified for a disability pension. The insurance institute assessed her care needs at a lower level than the Salzburg social office had done, and her case was raised in a question in Parliament (see http://www.parlament.gv.at/pd/pm/XXI/J/texte/018/J01819\_.html).

Recipients of care allowances are also exempt from telephone and radio/TV fees.

recipients of safe allowances are also exempt from telephone and radio 1 vices

## Age limits

None - all ages are covered (even the very young, since a recent reform).

## Means- and resources-testing, co-payment

For pensioners, there is no means-testing. Provincial schemes include some services for which charges are income-related.

#### Assessment

#### General definition

Section 4 of the BPGG states that entitlement depends on.. 'the permanent need for support and care as a consequence of a physical, mental or emotional or sensory disability that is expected to last for at least six months.'

# Specified impairments

Four specified impairments have fixed levels of attendance allowance, e.g. deafness and blindness = level 5.

#### Personnel

For the Federal Act, administered by the Pensions Institutes, the personnel involved are doctors, working in a structure which reflects that of the main pension. The medical report provided by a contracted doctor is reviewed by an Institute doctor and by a committee. Another committee makes the final decision.

There is some suggestion in the Andrea Mielke case (see above) that the pension institutes take a more technical-medical approach to assessment than the provincial social offices. However, the different authorities endeavour to align their approaches, and studies show that the provinces have similar distributions of awards (Austrian report, p.40).

#### Rules and instruments

A decree in 1999 set out specific care activities with corresponding allocations of time. The decree was developed in assessment rubrics which allow the assessor to add up the time per month arising from each activity in order to determine the relevant care level (*Stufe* 1-5, 50-180 hours per month). For the highest levels of care (*Stufe* 5-7) the medical report must indicate the nature of the exceptional need for care, e.g. when care is needed night and day (*Stufe* 6), or when the person is completely immobilised (*Stufe* 7).

#### Observation in context

It is recommended in guidance that the examination be conducted at home, but it does not have to be.

## Role of the disabled person

The disabled person must apply giving information about benefits received and other institutional data; there is no formal place for the person's own account of his or her care needs.

#### **BELGIUM**

#### **Provisions**

The provisions discussed in the national report are the federal Integration Allowance and the provision for Direct Payments by the Flemish Fund for the Social Integration of Persons with a Disability.

## Institutional Responsibilities

The Integration Allowance is federally financed and administered by the Ministry of Health.

Other provisions for needs related to independent living are made by the Communities. The Direct Payment scheme is specifically a Flemish Fund initiative and only operates in Flanders.

#### Nature of needs met

The integration allowance is intended to assist with the extra costs arising from functional impairments. Limitations in the areas of

- mobility (including movement outside the home)
- preparing and eating food
- personal care and hygiene
- household tasks
- living without supervision
- communication and social contact

are relevant in determining eligibility.

The direct payment scheme relates specifically to the use of personal assistants. The rules of the scheme do not delimit the activities of personal assistants, i.e. they may provide care, home help, assistance with mobility etc. See further discussion below on the scope for the disabled person to indicate the activities he or she seeks assistance with.

## Nature of provision

Integration allowance is paid in cash; there are four rates determined by extent of limitation. Direct payment scheme - a budget is granted on the basis of the person's limitations in performing ADLs. Ideally the budget corresponds to spending plans submitted by the disabled person; if it does not, the budget can be raised. Spending is expected to be related to the submitted spending plan which indicates the level of personal assistance to be financed and the activities covered.

## Linkages with other definitions of disability

The Integration Allowance is institutionally linked to the Income Replacement Allowance for the Disabled, and often entitlement to the two benefits is assessed together on the basis of the same evidence.

The direct payments scheme is subject to the same general definition of disability as all provisions of the Flemish Fund (including e.g. employment provisions) - see below: General definition.

## Age limits

Integration allowance is payable to people aged 21-65. For people over 65, there is a separate measure, the Allocation pour l'aide aux personnes agées, which provides benefits at a somewhat lower rate.

Flemish Fund - The Fund considers claims only those under 65, although once aid is awarded, the award can continue after 65.

Means- and resources-testing, co-payment

Integration allowance: if the beneficiary works, earnings above the level of the guaranteed minimum income are deducted from the allowance, and there is a general income threshold also.

#### **Assessments**

# Integration allowance

General definition

The allowance is intended for people with limitations in their ability to live independently.

Specified impairments

None

## Personnel

Doctors employed by the Ministry of Health do the initial assessments; although there is provision for a multidisciplinary assessment, in practice this only occurs if there is an appeal to a Court.

#### Rules and instruments

The legislation sets out a scale for assessing limitations to a person's ability to perform activities of daily life (ADLs). While the scale was purpose-designed for the legislation, it is similar to other ADL scales such as the Barthel and Katz, and to IADL scales (see the discussion in chapter 3 of the main report).

Observation in context

The person is usually examined at home.

Role of the disabled person

None specified.

# Direct payments by the Flemish Fund

#### General definition

To qualify for Flemish Fund provisions generally, a person must have a disability, defined as 'a long-lasting and substantial limitation of the possibilities of social integration due to reduced intellectual, psychological, physical or sensory capacities'.

#### Specified impairments

None

#### Personnel

Multidisciplinary teams do the initial assessment of whether the person is a disabled person. To determine the entitlement to direct payments, a multidisciplinary team is also involved; the final decision is made by a commission comprising people with a (physical) disability, parents of disabled people, experts and officials of the Flemish Fund.

#### Rules and instruments

- 1. The person's degree of disability is assessed using Barthel and Elida ADL scales along with other information about impairment. This information is used to place the applicant in a budget category.
- 2. The person's need for assistance is indicated by a detailed description (for a whole week, day by day, hour by hour) of the planned use of personal assistants. This description may be done by the multidisciplinary team in conjunction with the disabled person; however, two proposals can be entered if the parties do not agree.

#### Observation in context

The detailed description of the use of personal assistance is specific to the person's living conditions, environment etc.

# Role of the disabled person

This is an important feature of the direct payment system. The mechanism for producing an assistance plan is meant to allow the disabled person to indicate how he or she wants to organise his/her life. However, the national report comments that the element of self-definition relates to the assessment of needs, not to the initial judgment about whether the person is disabled for the purposes of general eligibility for Flemish Fund measures.

## **DENMARK**

## **Provisions**

The Law on Social Services (LSS) makes specific provision for care for both children and adults with disabilities (as well as other groups - children generally, terminally ill etc).

The Law on Social Pensions (LSP) provides for 'Outside assistance allowance' to people requiring continuous assistance when outside due to disability, and for 'Constant care allowance' (instead of outside assistance allowance) if the disability requires constant care or supervision'.

## Institutional Responsibilities

The municipalities are responsible for administering most provisions.

The counties also have responsibilities under LSS, particularly for more severely disabled people, for aids which are closely related to medical care, and for institutions. The counties have responsibility for the health service.

#### Nature of needs met

The stated purposes of the LSS include 'to improve the individual's opportunities for life experiences through contact, social and other activities, treatment, care and attendance'. Provisions cover:

- counselling
- personal care and assistance;
- assistance or support for necessary practical work in the home;
- assistance in maintaining physical or mental skills.

# Specific provisions include:

- payment of extra costs of maintenance (not for people receiving a social pension, except the most severely impaired), where such extra costs are a consequence of the impairment;
- provision for technical aids, consumer durables, car subsidy etc.

The LSP allowances cover extra costs related to care from another person (other types of cost appear to be implicitly included in the basic amounts for the social pension).

## Nature of provision

LSS: Individual needs determine the level of provision. However, there are some specific allocations. A specific allocation of 15 hours of attendance per month, saveable over 6 months, is available to 'persons under 67 whose freedom of movement is impeded due to substantial and permanent impairment of the physical or mental function', who are not receiving other forms of care.

Several articles of LSS are directed towards establishing flexibility in the way provision is organised, including:

- opportunity for the person receiving care to appoint a person to carry out the duties. The
  person so appointed shall be subject to approval by the municipal authority, which is then
  to agree with the appointee in writing as to the extent and scope of the duties, payment,
  etc.
- substitute or relief assistance to a spouse, parents or other close relatives providing care
- option for the municipality to pay a subsidy to any assistance engaged by the person where it is unable to provide the service itself
- option for some recipients (under 67 with substantial and permanent impairment) to choose the subsidy in preference to the service, although this may be overruled by the municipality, which may also choose to pay the carer directly.

Subsidies are paid 'by way of a fixed amount on the basis of estimated costs' (s.76(4)). LSS also contains detailed provisions on the circumstances in which a person can purchase technical aids from a supplier other than one contracted by the municipality or county.

LSP: specified cash amounts are payable (Constant care allowance amounts to approximately 2x Outside assistance allowance).

#### Linkages with other definitions of disability

None generally for LSS, but social pensioners are excluded from some provisions. LSP allowances are only for pensioners.

# Age limits

Certain specific provisions under LSS are only for those aged under 67. LSP allowances are payable only to pensioners aged 18-65.

Means- and resources-testing, co-payment

LSS: Assessments may take into account the resources of a spouse, but not of other relatives.

In the 1990s budget reforms, Danish public authorities were given much wider scope to introduce user charges. These have been introduced by some municipalities in care services, particularly for home help provisions.

LSP: The allowances are not means-tested.

#### Assessments

## General definition

Some provisions of the LSS are available to people 'with temporary or permanent impairment of physical or mental function'; however, specific measures are targeted on more narrowly-defined groups, as follows:

In the area of 'developing skills' the client group is 'persons with special needs due to substantially impaired physical or mental function or particular social problems'.

Provision for a cash subsidy for home help is made to people 'under 67 with substantial and permanent impairment of physical and mental function and in need of personal assistance and care and of support for the discharge of necessary practical work in the home'.

For subsidies towards the cost of engaging assistant carers, supervisors and attendants, the client group is 'persons with substantially and permanently impaired physical or mental function, with an activity level requiring special support'.

For deaf-and-blind persons there is specific provision for a special contact person.

Extra costs of living can be met for 'persons with substantially and permanently impaired physical or mental function' who are not receiving a social pension.

LSP: Outside assistance allowance may be granted to blind persons, persons with a severe visual impairment or persons otherwise requiring continuous outside assistance due to disability.

## Specified impairments

LSS: Deaf-and-blind are specifically mentioned (see above). The guidance on from the Ministry of Social Affairs on the LSS gives a number of examples of disabling conditions affecting e.g. breathing, speaking, consciousness (e.g. in cases of epilepsy) etc. The national report suggests that so many examples of conditions are mentioned of such a wide range of types, that they should be interpreted as illustrations of what is understood by disability rather than as limitations on eligibility.

LSP: Blindness/ restricted vision are specifically mentioned (see above).

#### Personnel

The assessment is done by a supervising nurse or a social worker. Home nursing is provided on the basis of a GP or hospital referral.

#### Rules and instruments

LSS: Extensive guidance is available on disabling medical conditions. Once a person is established as being disabled, the case worker assesses his or her ability to perform domestic and/or personal care tasks, to engage in social contact, move outside the home, etc. Various checklists and assessment rubrics are used for this, but they are open in structure due to the wide range of needs which can be recognised and taken into account.

## Observation in context

LSS: Assessments are usually done in the home, and specific circumstances are taken into account in evaluating individual needs.

# Role of the disabled person

Subsidies under LSS 'shall be payable subject to the ability of the recipient to administer the assistance, e.g. by engaging the necessary help and being responsible for the day-to-day planning of the work' (s.77(2)). More generally, choices of the mode of provision (see above under 'Nature of Provision') are intended to empower the disabled person to obtain the services most appropriate to his or her needs.

## **FINLAND**

## **Provisions**

The main independent living provisions discussed in the national report are those coming under the Law on the Provision of Services for the Disabled and its corresponding regulations.

## Institutional Responsibilities

The municipalities are required to survey and promote the living conditions of disabled people.

By specifying individual entitlements to services, and the service levels which might be expected, the state has imposed duties on the municipalities which may be enforced by individuals in the Courts. A number of cases have reached the Supreme Administrative Court, and a body of case law is developing on the rights created by the Law (Finnish report, p. 24).

## Nature of needs met

Specified needs include:

- moving
- communicating
- living at home
- need for another's assistance (in hours)

## Extra costs envisaged

- additional food costs
- costs from not being able to wear ready-made clothing

# Nature of provision

The law specifies individual entitlements to services, and the service levels which might be expected. For example, in order to define the entitlement to transport, 'a severely disabled person is one with a special difficulty to move and who due to his/her impairment or sickness cannot use public transport without excessive difficulty' (31.1.1995/ 102). Furthermore it is specified that a severely disabled person must be able to carry out at least 18 one-way trips a month in addition to the transport needed for working and studying.

The municipality determines the mode of provision, e.g. putting on a bus to provide transport services or offering reimbursement of taxi fares.

Linkages with other definitions of disability

None - provision is not institutionally linked to other benefits.

#### Age limits

None - elderly people are significant users of the services.

Means- and resources-testing, co-payment

None for services specified in the Act.

#### Assessments

## General definition

A disabled person is one who, due to impairment or sickness, has special difficulties in managing ordinary operations of life on a long-term basis (s.2 Law on Provision of Services to the Disabled).

#### Specified impairments

Generally not based on specified impairments, but mention of --

- mobility impairments leading to 'excessive difficulty' in using public transport
- severe speech impairments

## Personnel

Medical data is required, but the assessment of needs is done by social workers.

#### Rules and instruments

Apart from the Law and Regulation, further instruments have not been developed. Note development of guidance through case law.

## Observation in context

Social workers normally visit clients and observe them in their homes.

#### Role of the disabled person

The person must apply for the services.

The social services department must prepare a service plan in consultation with the person and his/her guardian.

#### **FRANCE**

#### **Provisions**

Invalidity pensioners of the social security system may receive the *Majoration pour Tierce Personne (MTP)*. Others (e.g. AAH recipients – see Appendix 1) may receive *Allocation Compensatrice au titre de la Tierce Personne (ACTP)*, or, from 1 January 2002, the *Allocation Départementale Personnealisée d'Autonomie* (ADPA) which replaces ACTP.

Pensioners who are unsuccessful in claiming MTP can also claim ACTP/ADPA. Old age pensioners may claim the *Prestation Spécifique Dépendance* (PSD).

The following discussion concentrates on ACTP/ADPA. The main change with the introduction of ADPA is that amounts paid are no longer recoverable from the recipient or his or her heirs, whereas ACTP was, in principle, recoverable.

## Institutional Responsibilities

Claims for ACTP/ADPA are assessed by the COTOREP but are made in the first instance through the local centre for social action, CCAS. The departmental-level administration for health and social action (Action Sanitaire et Sociale du Département, DASS) makes the decision as to the rate of ACTP/ADPA (from 40% to 80%) based on the assessment of the COTOREP.

#### Nature of needs met

ACTP/ADPA is oriented towards the need for personal care, but the activities to be done by the carer are not specified in detail.

#### Nature of provision

ACTP/ADPA is paid in cash. Where it is paid at the highest rate (80% of MTP), the recipient must prove that a carer is employed or that a member of the household acts as carer. For the lower rates of ACTP/ADPA (40-70%), demonstration of the assistance of a third person is not required.

Linkages with other definitions of disability

The recipient must have a general disability rating of 80%, as assessed by the COTOREP.

## Age limits

New claims for ACTP/ADPA are limited to those aged under 60, although once awarded these benefits continue in payment. Those over 60 may claim PSD.

Means- and resources-testing, co-payment.

ACTP/ADPA may only be received by those whose resources are assessed as falling below the social assistance level. There are specific rules for disregarding certain earnings in assessing resources.

## Assessment processes

#### General definition

ACTP/ADPA is payable to those aged 16-60 who have a rate of permanent disability (taux d'incapacité permanente) of 80%+ who require the assistance of another person for one or more essential activities of existence (actes essentiels de l'existence). The highest rate is payable to those who need assistance with the majority of essential activities and can demonstrate that they are being cared for by a person who is giving up the opportunity of paid employment, or is being paid for providing the care. The lower rates are payable to those who need assistance with one or more essential activities, and to those who need assistance with the majority of activities but cannot demonstrate that they have a carer who meets the stated conditions.

#### Specified impairments:

People who are blind are regarded as meeting the conditions for ACTP/ADPA.

Personnel: See Appendix 1 for a description of COTOREP personnel and structure.

## Rules and instruments:

The law does not contain a detailed breakdown of the essential activities of existence for the purposes of ACTP/ADPA. However, PSD is assessed using a national standard grid, the AGGIR. The components of this grid are the same as the spheres of autonomy in the Guide Bareme used by the COTOREP (see Appendix 1), i.e.

Coherence

Orientation

Personal hygiene

Dressing

Eating

Continence

**Transfers** 

Moving around inside the home

Moving around outside the home

Communication

## Observation in context:

Information not available.

## Role of the disabled person:

On the application form for ADPA, the applicant indicates the help he or she receives from members of the family, friends and neighbours, and support associations. The applicant also indicates if he or she does not have the help needed. In this case, the applicant writes down the help he or she needs to remedy the problems of daily life.

#### **GERMANY**

#### **Provisions**

One of the main provisions for independent living in Germany is care insurance (*Pflegeversicherung*), introduced in 1995 for domiciliary care and 1996 for institutional care. Care insurance is contributory, but from 1.1.1997, social assistance claimants have been brought under the statutory care insurance system, whereas previously they got equivalent benefits financed by the local authorities as part of social assistance.

Social assistance also includes provisions which may facilitate independent living. There are specific provisions for people in special life situations (*Hilfe in besonderen Lebenslagen*). For people with disabilities the main measures come under the rubric of integration assistance (*Eingliederungshilfe*).

# Institutional Responsibilities

The health insurance funds are the carriers for care insurance ("*Pflegeversicherung* follows the *Krankenversicherung*") and their medical advisors do the assessments. However the funding for care insurance is completely separate to health insurance, and issues arise about what should be paid for by each system, e.g. medical treatment in the home falls under health insurance.

Social assistance is delivered by the *Sozialamt*.

## Nature of needs met

Care insurance: The person's grade of 'care dependency' depends on the time needed for help with activities of daily life (ADLs) which include personal hygiene, eating and mobility (in the narrow sense - getting up, moving around the house). Help needed in domestic and household tasks is also included but has less weight in the cumulative total time which determines the grade.

Note that mobility outside the home is not covered; inability to leave the home is not grounds for receiving care insurance.

Integration assistance: includes provision of care, extra travel costs and costs of an accompanying person when travelling, training for the carer (*Betreuungsperson*) etc.

## Nature of provision

Care insurance: Services may be provided by organisations contracted to the care insurance system up to a certain cost level for each grade of care, or the claimant may choose a cash alternative. The cash alternative is just over half the cost allocation for provided care, but is more popular.

The medical advisor is meant to assess whether the required care can be secured with the cash alternative; care provided by contracted organisations is also checked.

Social assistance: This may also be delivered in cash in the form of e.g. financial compensation to the carer or allowances paid to the disabled person.

Linkages with other definitions of disability

Basically no linkages. The term 'disability' is not used in the care insurance field, and the concepts found in other areas (*Schwerbehinderte*, *Erwerbsminderung* etc) are not used.

While some social assistance provisions are specifically for disabled people, there are no automatic entitlements e.g. for a person who is registered disabled (GdB > 50%).

Age limits

None

Means- and resources-testing, co-payment

None for care insurance. All forms of social assistance are means tested.

# Assessments (Care insurance)

## General definition

It is emphasised that the person's care needs, not their medical condition, determines the entitlement to care insurance benefits.

The three grades of care dependency are specified as follows:

- I. Erheblich Pflegebeduerftige help needed with at least two ADLs once a day, home help needed several times a week. Altogether the need per day must amount to at least 1.5 hours, of which time for the basic care elements (hygiene, nutrition or mobility) must comprise at least 46 minutes.
- II. Schwerpflegebeduerftige help needed with ADLs at least 3x a day; home help needed several times a week. Altogether the care need per day must amount to at least 3.0 hours, of which the basic care elements must comprise at least 2.0 hours.
- III. Schwerstpflegebeduerftige help with ADLs needed 24 hours a day; home help needed several times a week. Altogether the care need per day must amount to at least 5.0 hours, of which basic care comprises at least 4.0 hours.

## Specified impairments

None. However, specific conditions have been discussed in debates about the scope of care insurance. In particular, there has been extensive debate about provision for people with dementia, who show a high rate of exclusion in care insurance assessments as their ability to do the tasks specified for assessment is not necessarily affected. New rules have been introduced to make more provision for this group.

#### Personnel

Nurses from the health insurance funds do the assessments.

#### Rules and instruments

Each allowable care component is tightly specified, and schedules allow the assessor to indicate the time taken for each component per day.

#### Observation in context

Assessments are conducted in the home.

## Role of the disabled person

Quite strict rules on what can be counted as care limit the scope for the person to define his or her needs. It is suggested that one reason for the popularity of the cash alternative is that limitations on the care that may be provided (e.g. social contact and companionship) do not apply to informal carers.

#### **GREECE**

#### **Provisions**

Pensioners and persons affiliated to social insurance institutions may receive a cash supplement if in need of care.

Disabled people receiving social assistance may also receive complements relating to their care/ ADL needs.

Others in need of care (particularly the elderly) may receive various local services in kind.

# Institutional Responsibilities

Pensioners are assessed and paid by the relevant insurer (IKA is the main insurer) (see Appendix 1).

The assessment of disability for non-pensioners is done by Health Committees formed and financed by the Regions of the National Health Service. Social assistance disability benefits, complements, and services are provided by local authorities.

## Nature of needs met

The exact needs intended to be covered by cash payments are not specified, but the emphasis is on care provision.

## Nature of provision

Cash is provided to pensioners and social assistance recipients; otherwise provision is in kind.

# Linkages with other definitions of disability

The main care supplements are only for pensioners, i.e. those who are work-incapacitated or elderly.

The Disability Card, now being piloted, is intended to provide a single passport to a range of provisions for disabled people. It is primarily aimed at those disabled from a young age, i.e. non-pensioners.

## Age limits

Information not available.

Means- and resources-testing, co-payment.

The care supplement to the pension and the complements to social assistance for the disabled are not means-tested. Care provisions in kind are generally means tested or subject to co-payment.

# Assessment processes

## General definition:

For pensioners, the care supplement is available for those suffering from paraplegia/ tetraplegia and absolute disability if the person is in permanent need of supervision, care and support provided by a third party.

## Specified impairments:

For pensioners, paraplegia/ tetraplegia are specifically mentioned as above.

For social assistance, there are special provisions for those with: blindness, spastic encephalopathy, thalassemy or AIDS, Hansen's disease, deaf-mutes, paraplegia and tetraplegia, severe mental retardation (IQ < 30) etc.

## Personnel:

Assessment is done by doctors. The first level Health Committees are organised around specialisms; the three main sectors are pathology, surgery and psychiatry, with subdivisions within them. The second level Committees (which deal with appeals) have representatives from the three main sectors.

## Rules and instruments:

The Guide for the Evaluation of the Disability Rate (1993) is applied by Health and Certification Committees.

## Observation in context:

The assessment focuses on the person's medical condition rather than living conditions and other personal and social circumstances.

## Role of the disabled person:

None specified.

### **IRELAND**

#### **Provisions**

Constant Attendance Allowance: this allowance is payable to occupational injuries (Disablement) benefit recipients only.

There are several allowances administered by Health Boards, including: Mobility Allowance
Motorised Transport Grant
Blind Welfare Allowance.

There is also a range of other benefits and concessions for the blind, including travel concessions, electricity, gas and telephone allowances and free TV licence.

Tax credits are also available: Registered blind people have an additional personal tax allowance. There is also a tax allowance for guide dog users and an allowance for employing a carer.

Health Boards provide home help services.

There are several allowances paid to carers (Carer's Allowance (means-tested), Carer's Benefit (contributory) and Domiciliary Care Allowance (for the parents of a disabled child) but no other allowances for purchasing care. The Carer's Allowance has its origins in a previous Prescribed Relatives Allowance. It is questionable whether it should be seen as a disability-related benefit, not only because it goes to the carer rather than the disabled person, but also because the criteria focus more on the means of the carer than on the needs of the care recipient.

Much of the debate about caring in Ireland has revolved around payments to carers. 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. In a recent select committee debate (Family, Community and Social Affairs Select Committee, 12 Dec 2001), the Minister restated the connection between removing the means test and developing medical control mechanisms. He argued that the Department (DSCFA) was not equipped to undertake detailed individual needs assessments and that this was a function more appropriate for health boards, and he reiterated the position that the primary purpose of social security benefits should be income support rather than the financing of a care system.

In 1998 a working group based in the Department of Finance reviewed the availability of allowances etc to promote care in the community as part of the Action Programme for the Millennium. It noted that, if the availability of provision for care was to be widened by removing the means tests on the Carer's Allowance, it would be necessary to ensure that there was a way of maintaining distinctions between care provided to those who were 'simply elderly (and perhaps a bit frail)' and those who were completely incapacitated (Department of Finance, TSG 98/45 Care in the Community). Subsequently, a needs assessment project was piloted by the Western Health Board, Co Mayo.

The current (as at 2002) conditions for receiving Carers Benefit or Allowance include the requirement that the person being cared for must be 'so incapacitated as to require full-time care and attention'. This requirement is not enforced very rigorously. The application form includes a section for a medical report on the person being cared for. The doctor gives the diagnosis and expected duration of incapacity, and indicates the person's functional capacities, using the same list as is used for the MRA system (for invalidity pension etc). There are no questions directly related to the need for care.

# Institutional Responsibilities

Constant Attendance Allowance is administered by the Department of Social, Community and Family Affairs (DSCFA).

Mobility Allowance, Motorised Transport Grant and Blind Welfare Allowance are administered by the regional Health Boards.

The Tax Allowance for employing a carer is administered by the Irish Revenue.

## Nature of needs met

CAA provides for care/ attendance in performing the necessities of life i.e. eating, sleeping etc.

The Blind Welfare Allowance can be seen as an allowance to meet extra costs arising from blindness, although these costs are not specified.

Mobility Allowance is a contribution to the cost of movement outside the home.

The tax allowance for employing a carer is not payable in respect of people employed as a housekeeper only.

Claimants in receipt of a disability benefit or Health Board payment can apply to their Health Board for a supplement to meet their special needs, such as heating and diet, under the Supplementary Welfare Allowance scheme (the residual social assistance system).

Health Boards may (but are not required to) make arrangements to provide care to people at home who would otherwise require institutional care. The usual practice is to provide home nursing and home helps, covering both medical and non-medical tasks.

# Nature of provision

CAA is paid in cash at three rates, for 'standard', 'severe' and 'exceptionally severe' disablement.

Other allowances are also paid in cash at standard rates.

The tax allowance may be claimed against taxable income. It is necessary for the carer to be formally employed (by a registered employer, with PATE taxation deductions) either directly or through an agency.

Health board home help services are always provided in kind (labour services) on the basis of an individual needs assessment.

Linkages with other definitions of disability

CAA is payable only to people who are 100% disabled by occupational injury or disease.

BWA can be claimed in conjunction with Blind Person's Pension, Invalidity Pension or the old age pension.

Age limits

CAA and BWA are payable to those over 18. Mobility Allowance is payable to those aged 16-66.

Tax allowance: no age limits.

Means- and resources-testing, co-payment

CAA is not means-tested.

BWA, Mobility Allowance etc are means-tested. Rates of benefit for Health Board payments are standardised, but there are differences between Boards in the means tests operated.

Only those with sufficient resources to employ a carer can utilise the tax allowance.

Home help services are subject to means-testing and co-payment.

## **Assessments**

## General definition

For mobility allowance, 'the applicant must be unable to walk, even with the use of artificial limbs or other suitable aids, or must be in such a condition of health that the exertion required to walk would be dangerous'.

The tax allowance is payable for care of an 'incapacitated person'; the claim form requires applicant to state 'nature of incapacity'.

For CAA, the person must be dependent on attendance for the necessities of life.

The current provision for carer's benefit and allowance requires that the person in need of care should require 'full-time care and attention' which means that the person receiving care is so disabled that he/she requires continual supervision to avoid danger to him or herself, or continual supervision and frequent assistance throughout the day in connection with his or her personal needs, for example help to walk and get about, eat or drink, wash, bathe, dress etc. In practice, a number of concessions exist regarding these requirements, e.g. 'full-time' does not mean 24 hours and 'frequent' does not mean 'continuous'. One important implication is that the carer does not have to be living with the person needing care.

# Specified impairments

As listed, there are a number of arrangements specifically for the blind and visually impaired.

#### Personnel

The decision on CAA is made by an official in the DSCFA, using the medical report available from the main claim for Disablement Benefit and possibly also a visit report from an official (non-medical).

Applications for a Mobility Allowance are accompanied by a statement from the person's doctor certifying the person's condition and that he/she is unable to walk. The final decision on the medical criteria lies with the Senior Area Medical Officer of the Health Board.

For Carers Benefit and Allowance, the medical certification of the person in need of care is done by the person's own doctor who completes a report giving diagnosis and expected duration, and summarising the person's capacities using the same listing that is used for income maintenance benefits.

#### Rules and instruments

Guidance on CAA is quite limited. Some basic ADLs are listed as examples but the official may interpret 'necessities of life' freely. In making a claim, claimants indicate:

- what they are unable to do due to the disablement
- what their carer or attendant does for them
- whether attendance is required daily, night and day etc.

The award of different rates of CAA depends on whether care is required part-time or full-time and day only or day and night.

There are four rules for Mobility Allowance: 1. unable to walk; 2. condition will persist for at least one year; 3. moving of applicant must not be forbidden for medical reasons; 4. applicant must be in a condition to benefit from a change in his/her surroundings.

# Observation in context

For CAA, a visit may be made in which the visitor records

- how the person actually spends his/her time
- help needed during the day and at night.

# Role of the disabled person

CAA guidance assumes a standard set of basic activities ('necessities') which the person will have to perform in daily life.

The individual needs assessments performed by health boards were criticised in a submission by the National Consultative Forum Subgroup on Quality to the Steering Group on the National Health Strategy 2001. The group argued for a greater role for patients and advocates at institutional levels (health board etc) as well as independent advocates to assist individuals in assembling a package of care.

## **ITALY**

### **Provisions**

Amounts for care needs are payable within both the insurance and the non-insurance systems. Within the social insurance system, pensioners who need the help of a third party to move around, or who require permanent assistance in order to carry out basic activities of daily life receive an allowance additional to the pension. Within the non-insurance system for 'civil invalidity', the most important benefit is the *l'indennità di accompagnamento* (accompanying grant) introduced by law n. 18 of 1980.

Reform proposals are under development which aim to establish a more unified structure of benefits, including a benefit to favour autonomous life and communication (*indennità per favorire la vita autonoma e la comunicazione*), an additional benefit for the most severely handicapped, and a benefit payable to carers of totally dependent old people (aged over 65).

## Institutional Responsibilities

INPS finances and administers payments to social insurance pensioners. The Ministry of the Interior is responsible for the *indennità di accompagnamento*.

The assessment for the *indennità di accompagnamento* is made by a Medical Panel, which is set up in each local administration (ASL) of the National Health Service.

### Nature of needs met

The *indennità di accompagnamento* is for those unable to walk without the permanent aid of a companion or those in need of continuous attendance due to inability to undertake activities of daily life.

## Nature of provision

The provisions discussed here are in cash.

## Linkages with other definitions of disability

Provision in the social insurance system is for recipients of invalidity or old age pensions. Provision in the non-contributory system is for those with a degree of civil invalidity technically equal to 100% (as for the income provision *pensione di inabilita* – see Appendix 1) who need the aid of another person. The relevant certification from the Medical Panel may also be the basis for the disabled person's carer to claim *permissi in favore di persone gravemente handicappate*, which give various rights to paid time off work.

## Age limits

No age limits for the *indennità di accompagnamento*.

Means- and resources-testing, co-payment.

No means-testing.

# Assessment processes

## General definition:

For the *indennità di accompagnamento*, the person must be classified as totally invalid (100% civil invalidity) and, in addition, be unable to walk or undertake ADLs without the aid of a companion. A person may be classified as a civil invalid and nonetheless be able to work; the *indennità di accompagnamento* may be paid to people in work.

The Ministry of the Interior endeavoured to confine the benefit to people with physical disabilities, but this was overruled by the *Corte di Cassazione*, which held that people with mental disabilities could also come within the scope of the 1980 legislation.

For *permissi in favore di persone gravemente handicappate*, a severely handicapped person is defined as one whose handicap has so reduced his or her individual autonomy that permanent, global and continuous assistance is needed (Art 3 of Act 104/1992).

Medical panels may classify a person as having slight, medium, heavy or severe handicaps. *Permissi in favore di persone gravemente handicappate* apply only to those classified as severely handicapped.

# Specified impairments

None

#### Personnel:

Medical Panels (MPs) make the determination of a person's level of civil invalidity, and also certify that the person is a "disabled person unable to walk without the permanent aid of a companion" or that he or she needs continuous attendance due to inability to perform activities of daily life, and/or that he or she is handicapped for the purpose of Act 104/1992. Medical panels comprise a medical examiner, who acts as chair, and two medical practitioners. The panel may be augmented with further medical experts according to the specific nature of the impairment. These experts are nominated by the relevant association, e.g. the National Union for the Blind, the National Association of Families of Subnormal Children and Adults, etc. The panel may also be joined by social workers and other experts, and the person's own medical practitioner may also intervene in the assessment.

The recommendation of the MP is transmitted to a local Medical Committee for Invalidity and War Pensions, an administrative body established by the Treasury and the Ministries of Interior and Defence. This committee also comprises medical practitioners. If it does not challenge the MP's recommendation, the MP can confirm its assessment.

## Rules and instruments:

Tables of congenital and malformative pathologies (*Decreto Ministeriale* 5.2.1992) are used. These are regularly updated, e.g. by Treasury circulars. These tables give either single percentage ratings to particular diagnoses (e.g. Altzheimers disease = 100%) or ranges (e.g. Downs syndrome = 75% or 100% depending on the severity of the condition, which in turn may be measured by IQ, but may also reflect the person's ability to carry out ADLs).

The MPs are also instructed to use the concepts in the ICIDH, but the tables provide a more specific guide and are regularly referred to.

## Observation in context:

A medical visit is arranged.

## Role of the disabled person:

There is increased emphasis on assessing the person's 'residual individual capability' and finding appropriate benefits and rehabilitative measures to facilitate integration. However, procedures for involving the disabled person in the development of assistance packages have not been developed.

## **NETHERLANDS**

### **Provisions**

Provisions for independent living and exceptional needs are divided between three main sets of measures:

WVG, which encompasses mobility assistance and home adaptations;

AWBZ, which meets special care costs;

ABW, the general social assistance system, which includes provision for extra living costs related to handicap.

WVG (1994) combined previous measures for workers under the invalidity pension scheme with measures for the elderly which came under social assistance.

## Institutional Responsibilities

WVG and ABW are administered by the municipalities. WVG is financed (in effect) from their general revenue; ABW is partly co-financed by central government. AWBZ is a national health scheme, separate from the main health insurance system (long-term care is seen as being uninsurable by the ordinary providers). It is administered by regional care authorities. Problems of co-ordinating WVG and AWBZ have arisen and there are pilot projects to improve links between them.

Nature of needs met (medical care, personal care, home help, mobility, social contact, extra consumption expenses)

WVG covers mobility and the adaptation of the living environment.

ABW meets extra consumption expenses for people with household income at the level of the social minimum (i.e. people on social assistance or with equivalent income, e.g. old age pensioners on the minimum AOW)

Historically, much AWBZ expenditure went to financing institutional care. AWBZ also finances nursing services in the home, and the development of personal budgets (see below) has seen AWBZ funds put to a wider range of purposes.

Nature of provision (whether services are provided or cash; if cash, standard amounts, reimbursement for actual expenditure; if services, extent to which individual entitlements are specified)

For WVG, both cash and services can be provided. Cash provision is usually in the form of reimbursement, i.e. it is tied to particular expenditures.

In the guide provided by the association of municipalities (VNG), mobility needs are not fixed: they are assessed individually on the basis of the person's regular social contacts and activities and the possible use of public transport. Similarly minimum requirements of the living environment are not specified.

Personal budgets under AWBZ (PGBs) were introduced in the mid-1990s. They are intended to facilitate the adaptation of services to the disabled person's preferences. A modernisation project for AWBZ is underway which will further promote deinstitutionalisation and address issues about the management of PGBs. PGBs are popular but patterns of spending are quite different to the pattern of service provision, leading to concerns about misuse.

# Linkages with other definitions of disability

A few municipalities link the administration of WVG, AWBZ and ABW provisions (NL 19). WVG assessment may serve as passport onto employment measures (REA). There is no link to the main income-providing measure (WAO).

# Age limits

WVG removes the previous distinction between provisions for those of working age (under AAW) and provisions for the elderly (through social assistance).

# Means- and resources-testing, co-payment

For WVG, the municipalities are required to establish rules about the criteria for provisions and then adhere to them ('open-ended' financing requirement). Rules may include requirements for co-payments and means tests (generally more like affluence tests, excluding the well-off).

There is usually some co-payment under AWBZ. ABW is means-tested.

## Assessments (WVG)

# General definition

Article 1.1 defines a handicapped person as '... a person who experiences demonstrable limitations in the field of living or of moving in and outside the dwelling, as a consequence of sickness or infirmity'.

## Specified impairments

No particular impairments have specified entitlements in the national law, and the guidance from the Dutch Union of Municipalities (VNG) does not specify entitlements flowing from impairments, although impairments are classified (see below).

## Personnel

In smaller municipalities, the WVG consultant is likely to have a social work background. Much of the assessment is contracted out to organisations employing staff with a medical or physiotherapy background. Larger municipalities are more likely to employ people with such skills themselves, and they are less likely to contract out the assessments.

#### Rules and instruments

Most municipalities follow an 'Indication Protocol' developed by the VNG. This protocol uses classification headings from the ICD and ICIDH-1 to provide a framework for assessment. The person's health status is classified using a list of headings which resemble those in the AMA Guides (see Appendix to WP1) - a mixture of diagnostic and impairment headings.

This is followed by an analysis of the claimant's limitations in a variety of fields. This listing is a mixture of the ICIDH-1 disability and handicap listings, and resembles the WHO's Disability Assessment Schedule (WHODAS II).

## Observation in context

In about 40% of cases the assessment takes place in the applicant's home.

# Role of the disabled person

An analysis is made of the activities that are hindered by the claimant's limitations. The choice of appropriate provisions is made in agreement with the claimant.

### **NORWAY**

## **Provisions**

There are relevant provisions under the National Insurance Act Folketrygdloven] (NIA) and the Social Services Act (Sosialtjenesteloven, SSA).

Provisions under the NIA include financial support to what is called 'improved functioning in daily life' for persons with disabilities (Sections 10-6, 10-7), coverage of extra costs related to disability (Section 6-3) and special care through private (family) arrangements (Sections 6-5, 6-5).

The national report focuses on one particular provision under the SSA, the Self-directed Personal Assistance (*brukerstyrt personlig assistanse*, BPA).

## Institutional Responsibilities

Municipalities provide services under the SSA in accordance with national guidelines.

The BPA is intended to be flexible and responsive to the individual circumstances of the disabled person, and largely for this reason it was decided to incorporate it in the SSA rather than in the National Insurance Scheme (Ot.prp. nr. 8 (1999-2000), which is administered by insurance offices.

## Nature of needs met

Most needs for practical assistance and training in daily life, including those relating to household tasks, personal care as clothing, hygiene, eating, social contact, support for participation in social and cultural activities, etc. The BPA is not usually meant to cover needs while one is taking part in other organised activity as work or education

The nature of needs met by BPA is not regulated, only the hours of paid help through BPA. In the guidelines produced by a user-directed co-operative for BPA the following are mentioned as tasks of an assistant: clean the windows, open a bottle of wine, clean your back in the bath tub, collect children from day care, do shopping, clean floors or make the beds, drive your car, fix your wheel chair, help you paraglide, write notes at meetings etc. According to this co-operative these tasks a personal assistance can do to enable and let a user have energy to perform daily life activities.

# Nature of provision

The provision is an entitlement to service, expressed in hours. The municipality decides the number of hours per week that the person is granted, and this may vary from one hour per week to 24 hours a day.

# Linkages with other definitions of disability

There is no formal link or relationship between definitions used in the context of BPA and the definitions of disability adopted in other contexts. However, some users may have been receiving domiciliary nursing, home help or other care services from the municipality before the issue of applying for BPA was raised and this may in practice influence the way in which assessments are made in practice.

## Age limits

The Ministry of Social Affairs strongly recommends that BPA users should be more than 18 years of age – the full legal age of Norway. The reason is that the user should be capable to define his/her own needs, instruct and guide the assistant on how the help ought to be given, set up and follow a work plan and handle other aspects of the supervisor role. The municipalities may in particular circumstances grant BPA to persons younger than 18 years of age. This decision should be based on the confirmation from other persons around the applicants (parents, other next of kin or guardians) that they are willing to take on the role of supervising and directing the assistant, at least in the beginning (Ot.prp. nr. 8, Para 4.2, SHD 2000: 2).

# Means- and resource-testing, co-payment

There is no means- or resource-testing or co-payment in BPA.

## Assessment processes

The assessment in BPA is dual; on one hand the assessment must ascertain that the person in question has substantial needs for assistance in daily life, on the other hand that the person has sufficient capability to use this particular form of assistance.

## General definition

The most general definition given is that a person has to have 'particular needs for assistance because of illness, disability, ageing or other reasons' in order to be eligible for BPA (Section 4-2 of the SSA). According to the law bill (Ot.prp. nr.8, Para 4.2) and the guidance of the Ministry of Social Affairs the primary target group for BPA are 'users with compounded (complex) and substantial needs for services' (SHD 2000: 2). Similarly, both documents emphasise that BPA is a provision meant for severely disabled persons (Ot.prp. nr. 8, Para 1, SHD 2000: 1).

In addition, it is required that the applicant is able to take on the role of being supervisor for the personal assistant. He/she must have sufficient self-understanding and resources to live an active life, both in his/her dwelling and outdoors (Ot.prp. nr. 8, Para 4.2, SHD 2000: 2).

## Specified impairments

It is stated explicitly in the law bill (Ot.prp. nr. 8, Para 4.2) and guidance (SHD 2000: 2) that BPA is not meant to be limited to particular disabilities, diagnoses or impairments, as long as the disability does not prevent the exercise of the necessary user-direction. These documents also mention that in particular cases a person with learning difficulties may be granted BPA. Thus no list of relevant and specific impairments is given. However, the 1990s pilots with BPA had been initiated by the main organisation of people with physical impairments. According to our informants and other research (Askheim 2000: 210-213; Askheim 2002: 6-7) most current users of BPA have substantial physical impairments, especially mobility impairments.

## Personnel:

Staff in the social and care departments of the municipalities administer the provision, in particular health personnel employed by the municipality (e.g. nurses) and occasionally social workers.

# Rules and instruments:

Guidance on BPA is quite limited. The stated recommendations are broad and unspecific. They leave much to the exercise of discretion by professional staff in the care and social services departments of municipalities. The guidance emphasises that municipalities must have this provision available for inhabitants who may potentially obtain a more active and independent life if granted BPA. It recommends that only applicants with sufficient understanding of their own needs and competence to supervise the assistant should be granted BPA, and some administrators view this as ruling out persons with mental or social impairments.

No written form is needed when applying for BPA, but most local officers produce a written evaluation report to a superior officer and give recommendations of the hours of BPA needed. The superior officer then give recommendations what should be provided as BPA service and what should be provided as other type of services (home care, domiciliary nursing, occupational therapy [ergoterapi], physiotherapy and likewise). These will all be parts of most municipalities' health and service provisions. The local service administration is supposed to design an overall 'care and service package' that is appropriate to cover the total needs of the disabled person. Some administrations still regard the BPA service being a 'plus care' service provision. Other municipalities use BPA actively as a care service for people needing extended care and service (including old persons and persons being seriously ill).

A semi-private agency established by the Ministry of Social Affairs and the Norwegian Association of Local Authorities (*Kommunenes Sentralforbund*), *Ressurssenter for omstilling I kommunene* – *RO*, provides information and guidance on how the municipalities should plan, implement and practice BPA.

## Observation in context

The responsible health, care or social service worker will normally visit the home of an applicant in order to assess the person's needs and abilities, practical hindrances and estimate the hours of need of BPA. If the applicant is a prior user of other care services in the municipality his/her circumstances will already be known to staff in the health, care or social service, and observation in context will not be required.

## Role of the disabled person:

Under Section 8-4 of the SSA the municipality has a duty to consult the applicant, that is, the package of services shall as far as possible be designed in co-operation with the user, and his/her views are be given substantial weight. More specifically, this provision explicitly empowers the disabled person both to define his/her needs when applying for BPA and to have a voice in how these needs are best met. BPA is an alternative way of organising practical and personal help for severely disabled who require assistance in daily life, both within and outside the home. The user has a role as work supervisor and takes on a responsibility for the organisation and substance of the assistance in relation to his or her needs. Within the number of hours per week allocated by the municipality, the user is in principle free to decide whom he/she will as helper(s), what the assistant(s) will do, where and at what hours the help is to be given.

It is a key requirement that the disabled person can be work supervisor for the assistant, not that he/she necessarily should be the employer of the assistant. Three different models of employing organisation have emerged; the municipality, a co-operative (andelslag) of users or the individual user may all be the formal employer of the assistant(s).

## **PORTUGAL**

## **Provisions**

An important new provision was announced in 1999 and introduced in 2000 (Decree n.º 309-A/2000 of 30 November): the Long-term Care Supplement (*complemento por dependência*). This supplement is payable to old age, disability and survivor pensioners of both the contributory and non-contributory regimes. Previously only the severely disabled (*grande invalidez*) in the contributory scheme received this benefit.

## Other provisions include:

For industrial injuries and occupational diseases (*Acidentes de Trabalho e Doenças Profissionais*)

- Supplementary care benefit (*prestação suplementar por assistência de terceira pessoa*): Pension supplement for severely disabled persons requiring constant attendance. Amount up to the ceiling set for minimum wage for household workers.

#### Social action:

For persons in need of temporary or permanent, light or severe care for physical, mental or social reasons.

# Institutional Responsibilities

Policy oversight is in the hands of the *Ministério do Trabalho e da Solidariedade*. Administration of the *Complemento por dependencia* is by district centres of solidarity and social security (*Centros Distrital de Solidariedade e Segurança Social*).

Measures are co-financed between central government and the provinces.

# Nature of needs met

Cash provision centres on personal care needs. Limitations in hygiene and eating are specifically mentioned.

Social action includes social contact (day centres etc).

# Nature of provision

Provisions linked to benefits are in cash. Amounts are fixed according to the degree of dependency (there are two degrees). For recipients of contributory pensions, amount is 50% or 90% of the social pension level; for non-contributory pension recipients, it is 45% or 75% of the same base amount.

The application must identify the person who will give the care.

Social action is in kind.

Linkages with other definitions of disability

Requirement to be a pensioner – but provisions are for old age as well as disability pensioners.

# Age limits

Separate provisions for children needing care. No upper age limit.

Means- and resources-testing, co-payment.

There is means-testing within the main rules for the non-contributory pension; otherwise not.

# Assessment processes

## General definition:

There are two levels of dependency:

- 1.º Individuals that cannot autonomously undertake actions which are indispensable to the satisfaction of the basic necessities of daily life;
- 2.º Individuals that find themselves in the previous situation and are bedridden or present symptoms of serious dementia.

# Specified impairments:

There are some impairments specified for 'fast-track' entitlements, e.g. HIV and multiple sclerosis.

### Personnel:

Applicants must provide a medical report with their application which endorses the dependence situation. The decision is made by officials.

### Rules and instruments:

The widespread availability of care supplements is a new measure, and the setting of just two levels of dependency is seen as reflecting the lack of experience and jurisprudence in this field.

Observation in context:

None specified.

Role of the disabled person:

Not specified.

## **SPAIN**

### **Provisions**

Extra amounts for care needs are payable within the contributory and non-contributory income maintenance systems. Independent provisions for care needs do not exist.

There are also separate ad hoc provisions for people with difficulties using public transport.

# Institutional Responsibilities

Contributory benefits are paid by INSS (National institute of social security). The Institute of Migration and Social Services (IMSERSO) has policy oversight of non-contributory benefits; autonomous communities are responsible for administration and financing of non-contributory invalidity benefits.

## Nature of needs met

Provision is for personal care needs.

# Nature of provision

Provisions linked to benefits are in cash.

# Linkages with other definitions of disability

Provision in the social insurance system requires the applicant to establish that he or she is permanently totally incapable of work (*incapacidad permanente absoluta*) and, in addition, that the disablement is sufficiently severe to require the aid of another person (*Gran invalidez*).

Provision in the non-contributory system is for those with a degree of disability or chronic disease equal or over 75% who need the aid of another person.

# Age limits

New awards of insurance benefits only to age 65; no age limit once awarded. Non-contributory supplement of 50% limited to those aged 18-65 who are 75%+ disabled; more discretionary/ in kind provision under general social assistance available for (other) handicapped persons and elderly people lacking enough income and with a difficult social and family situation.

Means- and resources-testing, co-payment.

General social assistance provisions are means tested.

## Assessment processes

## General definition:

In both contributory and non-contributory systems, the person must, due to anatomical or functional losses, need the help of a third person to carry out essential daily tasks.

# Specified impairments

None

### Personnel:

Doctors of the social insurance system (for contributory benefits) or multidisciplinary teams (non-contributory) make the decisions.

## Rules and instruments:

The Guide *Valoración de las situaciones de minusvalía* (VM) includes a section on assessment of care needs (Baremo para determinar la necesidad de asistencia de otra persona). It is divided into sections on disposition (whether confined to bed, etc), self-care (getting up, going to bed, dressing, personal hygiene, eating), communication, security and orientation, special needs (e.g. use of specialised medical equipment), and personal and social adaptation. Each section contains statements which have a certain allocation of points attached to them. To qualify for assistance, a person must get at least 15 points.

## Observation in context:

It is usual, but not required, for the assessment to be done in the home.

Role of the disabled person:

None specified.

#### **SWEDEN**

## **Provisions**

The three main sets of independent living provisions discussed in the national report are:

- 1. The Handicap Allowance administered by RFV (a social security provision),
- 2. The Laws concerning Support and Service for Certain Groups of Disabled (LSS) and Compensation for Assistance (LASS) and
- 3. The Social Services Act (SoL) which are administered by the municipalities.
- 1. The Handicap Allowance may be paid to
  - provide help from another person in daily life
  - meet considerable extra living costs.

It may also be used to provide support to people in employment (see under employment measures).

A similar allowance, the Care Allowance, is payable to facilitate care in the home of disabled children.

- 2. A range of measures is provided under LSS; here we focus on the personal assistance provisions which are specifically regulated by LASS.
- 3. SoL provides for needs which partly overlap with LSS/LASS. However services provided under SoL may be charged for (subject to a means-test) and the level of entitlement is defined more restrictively. SoL leaves more discretion in the hands of the municipalities. It is therefore more advantageous to have the status of a severely disabled person for the purposes of LSS/LASS. SoL is not based on the special provision of services to the disabled: it is based on the principle that everybody should have a 'reasonable level of living'.

The difference between eligibility for LSS/LASS and for SoL comes down to the severity of the disability; the national report suggests that medical certification is increasingly used to set this borderline.

# Institutional Responsibilities

Handicap allowance and care allowance are paid by the Social Security Board (RFV). LSS/LASS and SoL are administered by local authorities and financed under mixed central-local funding models.

#### Nature of needs met

(medical care, personal care, home help, mobility, social contact, extra consumption expenses)

For Handicap Allowance, care needs and costs relating to housing, diet etc are covered. Care needs are taken to include personal care (bathing etc) and housework like cooking, cleaning, laundry, bedmaking

- continuous attention counts as care time
- intensity and frequency is assessed

Extra costs of living may include:

- home adaptations
- special appliances
- food, clothes and other consumption items
- extra medical costs

LSS/LASS covers services such as residential and respite care, day activities etc and the provision of personal assistance.

The main services under SoL include transport assistance, home helps and other care, and sheltered/ serviced accommodation.

## Nature of provision

Handicap allowance is a cash allowance. The allowance is paid at three levels: 69, 53 or 36% of the basic amount (the numeraire for cash benefits).

LSS governs the provision of services. Ten different services are specified in the law. LASS introduces ideas of the independent living movement through the way that care provision is organised. Under LASS, the service-user has the right to employ the assistant, i.e. the municipality may provide cash to pay for an assistant. Alternatively the municipality may employ the assistant.

SoL: Under the 1997 amendment to the Social Services Act, social assistance was divided into two main categories:

- a) (economic) maintenance encompassing the most basic needs (food, clothes, housing, articles of consumption etc);
- b) other forms of social assistance and services (mobility services, home help, housing including special service and care for the elderly and disabled). While a specific national guideline for cash assistance under (a) was introduced, there is no guideline for (b). 'How much, and what kind of services to be delivered to the disabled, are issues that rest with the social welfare office in the local municipality.' (Swedish report, p.14).

Linkages with other definitions of disability

Handicap Allowance: No relationship to disability benefit assessment despite institutional link. Note that aid to people in employment is encompassed within the same measure.

Other provisions: no linkages.

Services under SoL are institutionally linked to cash social assistance provision, but many elderly recipients (in particular) only use the service assistance provisions of the municipality.

# Age limits

Handicap Allowance: 16-64 (note Care Allowance for children) LSS/LASS only covers people below the age of 65. SoL – all age groups

Means- and resources-testing, co-payment

Handicap Allowance: no means-testing, cash payment

LSS/LASS: no means-testing or co-payment SoL: means-tested and subject to co-payment

## **Assessments**

# Handicap allowance

General definition of disability

## Specified impairments

Blind or deaf (or with severe hearing impairments) are always entitled to the allowance.

## Personnel

Medical data are required, but the assessment of needs is done by RFV officials.

## Rules and instruments

There is a set of RFV recommendations on what should be taken into account; however the approach is highly oriented to the circumstances of the individual case.

The translation of each care need into minutes and hours is done by the official - there are no standardised time allocations for different needs (check).

Consumer price information (from Konsumentverket) is often used to assess extra costs for food, clothing etc.

## Observation in context

Either the person comes to the office or officials visit clients and observe them in their homes. Visits are seen as often being helpful to making the assessment.

# Role of the disabled person

The person must apply for the allowances.

## Personal assistance under LSS/LASS

#### General definition

A disabled person is a person with 'large and persistent difficulties in managing daily life'.

# Specified impairments

The law divides severely disabled people into three subgroups:

- a) persons with intellectual impairments;
- b) persons with lasting mental dysfunction after damage to the brain brought about by violence or physical illness;
- c) persons with other physical or mental disabilities that are not clearly linked to normal ageing.

## Personnel

Medical data is required, but the assessment of needs is done by social workers.

# Rules and instruments

#### Observation in context

The relevant professionals normally visit clients and work through their care plan with them in their homes.

## Role of the disabled person

This is an important feature of LASS, which has the aim of empowering the user. Specific provisions include the user's right to employ the personal assistant or, if the municipality employs the assistant, to select the person. The disabled person also has the right to decide what kind of help the assistant should give and in what way (Swedish report, p.13).

# Social services under SoL

General definition of disability

None

Specified impairments

None

## Personnel

Social workers. Medical data are not required.

Rules and instruments

No national guidelines.

Observation in context

Social workers normally visit clients and observe them in their homes.

Role of the disabled person

The person must apply for assistance.

## UNITED KINGDOM

## **Provisions**

The UK report discusses Disability Living Allowance (DLA), which is a social security benefit paid in cash. Other measures to facilitate independent living include domiciliary care provided by the NHS and community care provisions administered by local authorities. Community care provisions are based on an assessment of need and are means-tested. Provision always used to be delivered in kind as local authorities could not pay cash benefits; however, cash payments (called 'Direct Payments') were instituted in the Community Care (Direct Payments ) Act 1996 and currently the government is encouraging their more extensive use.

DLA may be claimed by any person under 65 with care or mobility needs, and can be paid in conjunction with other benefits, with the exception of overlapping provisions in the Industrial Injuries and War Pensions schemes. DLA may also be paid to people who are working or who are not receiving income maintenance benefits for any reason. There are no contribution requirements.

A related provision is the Invalid Care Allowance, payable to carers of disabled people, including people on the middle and higher rates of DLA.

## Institutional Responsibilities

The Department of Work and Pensions (previously called the Department of Social Security) is responsible for DLA. Assessments and payments are done by the Benefits Agency (an agency of DWP).

*Nature of needs met* (medical care, personal care, home help, mobility, social contact, extra consumption expenses)

The care components of DLA provide for help with bodily functions including washing and personal hygiene, getting up, dressing etc and taking medication, as well as supervision and watching over (e.g. when the person may harm him or herself). DLA is not intended to provide specialist domiciliary medical care, which is the responsibility of the NHS.

The mobility components are payable to people who 'need help getting around' including people who can walk etc but need guidance. Conversely, a person who has limited ability to walk may not be eligible if he or she cannot show that guidance or supervision from another person will facilitate mobility out of doors.

*Nature of provision* (whether services are provided or cash; if cash, standard amounts, reimbursement for actual expenditure; if services, extent to which individual entitlements are specified)

DLA is paid in cash.

# Linkages with other definitions of disability

The assessment for DLA is quite separate and distinct from the assessment of incapacity to work (see Appendix 1). Nonetheless, DLA serves as a passport to entitlement for the Disabled Persons Tax Credit (DPTC) for people in work.

DLA receipt is also one of the main bases for award of a disability premium in the Income Support (IS – means-tested social assistance) scheme.

# Age limits

DLA is payable to people who need care and/or help with mobility before their 65th birthday, but may continue in payment (once awarded) after 65. People making their first application after age 65 may claim Attendance Allowance, which is paid at two rates which roughly correspond to the two higher rate care components of DLA. In effect, therefore, people over 65 are excluded from mobility payments and from provision for less severe disability giving rise to care needs.

DLA is not means-tested.

#### Assessments

### General definition

DLA mobility component is a benefit for people who 'have difficulties getting around'. DLA care component is for people with 'care or supervision needs'.

# Specified impairments

People who are deaf and blind, and people who have lost their legs, have automatic entitlements.

# Personnel

The decision is taken by a BA decision-maker. Medical guidance may be sought where there are discrepancies between the person's medical condition and the stated care needs, or other difficulties in interpreting the medical evidence. However, it is emphasised that the Medical Service cannot determine claims nor advise directly whether the person satisfies a disability test.

Only a minority of claimants are referred to medical services for an examination. The person's own doctor (GP) may complete a brief statement at the back of the claim pack on the person's condition, and the decision maker may ask the GP or hospital for a report.

# Rules and instruments

Decision-makers follow detailed guidance which defines terms and specifies levels of attention, e.g. both day and night attention is needed for a person to qualify for the highest rate for care.

For the lowest rate of the care component, a person must either require a certain level of attention for personal care or satisfy the 'cooking test', also known as the 'main meal test', which examines a person's ability to cook a fresh meal 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. This test is stated to be intended to measure a person's physical and mental capacity to carry out complex functions.

## Observation in context

None. The decision is made on the basis of the application form and supplementary information. Decision-makers are directed <u>not</u> to take account of where people live or the nature of their work.

# Role of the disabled person

The person making the claim has to complete a form which includes a section for applicants to provide their own assessment of how their condition affects them. This 'self assessment' allows applicants to give their own account of their care needs. This account is assessed against rules setting out what needs are admisible. However, some rules are independent of the person's own needs and preferences, notably the cooking test. 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 .