



MODELIZAÇÃO DAS POLÍTICAS E DAS PRÁTICAS DE INCLUSÃO SOCIAL DAS PESSOAS COM DEFICIÊNCIAS EM PORTUGAL

AN INTERNATIONAL PERSPECTIVE ON MODELLING DISABILITY POLICY-MAKING

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Realizado no âmbito do Estudo “Modelização das Políticas e das Práticas de Inclusão Social das Pessoas com Deficiências em Portugal” promovido pelo **CRPG – Centro de Reabilitação Profissional de Gaia** – em parceria com o **ISCTE – Instituto Superior de Ciências do Trabalho e da Empresa**.

Disponível em www.crbg.pt.



Apoio:
Programa Operacional de Assistência Técnica ao QCA III – Eixo FSE



TABLE OF CONTENTS

I.	Introduction	p 3
I.1.	Relevance of the International Framework	
I.2.	Historical background: The European Social Welfare State	
II.	International Policy Instruments	p 6
II.1	The UN Convention on the Rights of People with Disabilities	
II.2	The EU Disability Strategy 2004 – 2010	
II.3	The Disability Action Plan 2006 – 2016 of the Council of Europe	
III.	Trends, tendencies and prevailing concepts	p 11
III.1	Holistic approach to disability	
III.2	Mainstreaming	
III.3	Community-based rehabilitation services	
III.4	Ageing and disability	
III.5	User-Involvement and User-Centredness	
III.6	Justification of Services	
III.7	Quality of Disability-Related Services	
III.8	International Classification of Functioning, Disability and Health	
III.9	Employment of People with Disabilities	
IV.	International Case Studies	p 21
IV.1	The Netherlands	
IV.2	Norway	
IV.3	Ireland	
V.	Key Issues and Challenges in Policy Implementation	p 54
V.1	Disability Rights Legislation	
V.2	Direct Payments	
V.3	Individual Needs Assessment and Planning	
V.4	Eligibility for Social Protection	
V.5	Early Intervention	
V.6	Outcome Related Funding	
V.7	Case Management	

VI. The EU regulatory and policy framework for social services and health services

p 59

- VI.1 EU competence in health and social matters
- VI.2 Definition and scope of health and social services
- VI.3 Social services as services of general interest
- VI.4 Social services as an economic activity
- VI.5 Application of internal market rules to health and social services
- VI.6 Application of public procurement rules to health and social services
- VI.7 The application of state aid rules
- VI.8 Other EU policy mechanisms and initiatives that impact on national disability strategies

I. Introduction

I.1. Relevance of the international framework

Although social policy generally emerges from national or regional economic, cultural and political traditions and becomes specified in formal legal, regulatory elements and informal processes and customs, the influence of the international context, through legal instruments, guidelines, models or paradigms, has been particularly strong in the disability sector over the past 25 years.

Consequently, the design of a National Disability Strategy needs to take account not only of (potential) legal obligations and ensure that policies are compatible with these but it should also look to other (relevant) jurisdictions to identify innovative and progressive approaches and occasionally to learn from their errors. Ultimately, the international context in the disability field is a rich seam of inspiration precisely because it results from reflection and comparison of best practices, and is not simply restricted by legal, economic and political realities.

This paper attempts to pull together the international perspective in two ways. In the first place, it provides a review of the evolution of certain global tendencies in the disability and social policy fields and describes three main international instruments that are currently in the process of being implemented.

The three main international policy instruments that are described are:

- The UN Convention, which will become legally binding from the moment a sufficient numbers of countries have ratified it.
- The EU Disability Strategy, which reflects the main tendencies and beliefs in the EU Member States.
- The Disability Action Plan 2006 – 2015 of the Council of Europe, which was also approved by Portugal, but only serves as a guideline for policy-makers.

Secondly, this document provides three jurisdictional case studies, from the Netherlands, Norway and Ireland, from which it is possible to draw some conclusions about how to go about developing a National Disability Strategy. Thirdly, some lessons learnt from other jurisdictions are presented. Finally, it is explored the EU regulatory and policy framework for social services and health services.

1.2. Historical background: the European Social Welfare State

The origins of the European Welfare State can be found in the thirty year period that spans from 1950 to 1980. It was a time of stable democracy, in which economic prosperity provided a robust foundation for socio-economic unification. Economic growth was strong, employment levels were high, and national budgets were balanced. In addition, the demographic profiles of the European States were compatible with developing approaches to welfare, based on significant transfer payments and taxation.

However, this European Welfare State Model began to come under pressure in the early 1980s. Previously favourable conditions began to dissipate and new factors and changing circumstances increased the momentum for change over the next twenty years. These factors included the oil crisis of the 1970s, which shook the foundations of European economic prosperity; the end of the Cold War, which undermined some of the crucial arguments in favour of the European Welfare State; the emergence of globalisation, which opened European markets, including labour markets, to increased competition and initiated the decline of industrial production and the evolution of a post industrial society.

At a political and economic level, the most significant critique of the European Welfare State was generated by the monetarist movement. In particular, this critique highlighted the tendency for welfare approaches to create a burden of dependency within the population, the growth of bureaucracy within the instruments of the State, the increasing consumption of Gross National Product (GNP) by the State, and the resulting untenable tax burdens created alongside spiralling national debt.

The socio-economic and political context continues to evolve, and with it, increasing challenges are emerging that make it impossible to conceive of a return to previous pre-1980 conditions. In particular, the structure of the family has been evolving, in terms of the disappearance of traditional family units and the increasing diversity in the way in which European citizens respond to changing social structures and economic conditions.

Of particular importance are the changes apparent within European labour markets, in terms of the increasing flexibility of the labour market, in which it is unusual for a worker to be employed in the same job throughout his or her working life, the increasing shift to part-time working, and the radically changed skill requirements within the labour market, where many traditional skills have become obsolete.

In addition, the demographic profiles of most European Member States are evolving in such a way that a smaller number of the population will be required to support an increasingly older and more dependent population. Finally, Governments are working within increasingly less flexible spending regimes as is well illustrated by the convergence criteria specified for membership of the European Monetary Union.

At this point, there is a general consensus that welfare reform is urgently required and that these reforms must be based on structural and system change. What is required is a shift in paradigms, which will bring with it new risks and new opportunities. European Member States now face a series of fundamental social and political decisions that will have wide-ranging implications for the provision of rehabilitation services in Europe. Some of the more important dilemmas are described below.

- New approaches must be designed to support economic growth and prosperity, rather than focusing on the redistribution of income and compensatory benefits.
- New approaches emphasise the individual's obligation to society, rather than his or her rights and claims against society.
- New approaches will target specific vulnerable groups for support, rather than enabling the horizontal redistribution of wealth.
- New approaches will be based on the principle of equal opportunities, rather than the provision of supports and intervention.
- New approaches will have as their aim the activation of economically inactive workers, rather than supporting people in dependent positions.
- An important strategy to support such changes will be increasing competition and privatisation of services, rather than supporting public provision.

In the case studies it is possible to perceive that these general factors impact differently in different jurisdictions depending on the demographics, economics and social policy legacy of each Member State.

II. International policy instruments

II.1. UN Convention on the Rights of People with Disabilities

The Convention on the Rights of People with Disabilities and its Optional Protocol was adopted on 13 December, 2006, at the United Nations Headquarters in New York, and was opened for ratification on 30 March, 2007. It marks a “paradigm shift” in attitudes and approaches to people with disabilities. The Convention is intended as a human rights instrument with an explicit social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities, and identifies areas in which adaptations have to be made for persons with disabilities to effectively exercise their rights and areas in which rights have been violated, and where protection must be reinforced

There is no doubt that existing human rights treaties are intended to promote and protect the rights of all people, including people with disabilities, but it has become clear that these mechanisms have failed to ensure that people with disabilities have an adequate level of protection. The Convention attempts to address this. It does not contain any new human rights, but sets out how existing rights within the wider body of international human rights law can be supported and actualised.

The Convention formulates some concrete guidelines and recommendations for national/regional policy-makers in designing their overall disability strategies:

- The principles underpinning the Convention should be taken into account in specifying national principles. These are:
 - Respect, dignity and autonomy
 - Non-discrimination
 - Full and effective participation
 - Respect for difference and acceptance of disability as part of human diversity
 - Equality of opportunity
 - Accessibility
 - Gender equality
 - Respect for children
- *Inclusion in the community:* A central premise of the Convention is that people with disabilities flourish best within their community, and that they have a contribution to make to their community. This may require support, but is a necessary commitment.
- *Getting rid of stereotyping:* Everyday interaction with people with disabilities is the best way to remove stigma. Governments, communities and, crucially, networks that represent sectoral stakeholders and civil society, can make this happen. The Convention calls on States’ Parties to promote awareness of the capabilities and contributions of persons with disabilities and to promote recognition of their skills, merits, abilities, and contributions to the workplace and labour market.

- *Work and employment.* Article 27 on Work and Employment give a clear and unequivocal message that people with disabilities should be able to participate in the workforce on an equal basis with others. Recommended actions include affirmative action programmes, incentives and other measures that mainstream workplaces to job seekers with disabilities and a greater focus on job retention measures for workers already in employment who acquire a disability.
- The issue of *definition of disability* was one of the most troublesome. It was resolved in the end by a preambular paragraph which recognizes "that disability is an evolving concept and... results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others".
- Finally, it should be stressed that despite the overall tendency to mainstreaming and an inclusive society, the Convention contains a specific Article (26) on the need for *habilitation, rehabilitation* and support programmes or services. These services should be comprehensive, multi-disciplinary and have as their objective the independence and full participation of people with disabilities in society. The Article confirms the need to address the integration of people that acquire a disability and to enhance the independence and participation of those that have a disability from birth (habilitation).

II.2. EU Disability Strategy 2004 – 2010

Equality of opportunity is the objective of the European Union's *long-term strategy on disability*, which aims to enable disabled people to enjoy their right to dignity, equal treatment, independent living and participation in society. Actions undertaken by the European Union underpin the set of common EU economic and social values, by enabling disabled people to fulfil their capabilities and participate in society and the economy.

The EU Strategy is built on three pillars:

- (1) EU anti-discrimination legislation and measures, which provide access to individual rights;
- (2) Eliminating barriers in the environment that prevent disabled people from exercising their abilities; and,
- (3) Mainstreaming disability issues in the broad range of Community policies which facilitate the active inclusion of people with disabilities.

The *EU Disability Action Plan* (DAP) - established by the European Commission to ensure a coherent policy follow-up to the 2003 European Year of People with Disabilities in the enlarged Europe - provides a dynamic framework to develop the EU disability strategy. In the changing EU economic and social environment, structured mainstreaming of disability is indispensable. Disability policies are essentially the responsibility of Member States, but Community policies and actions impact in many ways on the situation of disabled people. The Council acknowledged this and recommended that Member States take full account of the DAP when developing national disability policies.

Phase 1 (2004 – 2005)

The first phase of the DAP focused on disabled people's access to the labour market and to employability-related measures such as lifelong learning, information technology and access to the built environment. Two important developments during this phase were the Employment Equality Directive and the Commission on the Regulation of State Aid. The *Employment Equality Directive* prohibited direct and indirect discrimination as well as harassment and instructions to discriminate on a number of grounds including disability.

Specific provisions to promote equal treatment for disabled people are included such as the requirement on private and public employers to make reasonable accommodations to enable people with disabilities to have access to, participate in or advance in employment, or to undergo training.

The Commission *Regulation of State Aid* included employment provisions which enabled Member States (under certain conditions) to create incentives for employers and sheltered workshops to recruit and retain workers with disabilities. This has created an exception to the general rule that Member States cannot provide subsidies that can distort fair competition.

A preliminary analysis of the first phase shows that mainstreaming of disability aspects succeeded in some areas, notably in employment, ICT and education (eLearning).

Phase 2 (2006 – 2007)

Based on an analysis of Phase 1, the second Phase maintained employment for people with disabilities as a priority, but added access to high quality and affordable *support and care services* as a new element. In this respect, quality assurance became a priority and the possibility of a European quality framework has been raised. De-institutionalization and the creation of community-based services is a strong recommendation in the second Phase.

Another priority, introduced in the second Phase, is the *accessibility* of goods and services. Thus, in addition to the accessibility of physical infrastructure introduced in Phase 1, increased accessibility of services, transport and ICT, including a new generation of assistive systems, have been added.

Phase 3 (2008 – 2009)

As a result of consultation amongst the EU Member States, both accessibility and employment will continue to be priorities during the last Phase of the DAP. The main remark regarding accessibility is that it should be understood in a wide context. The European Disability Forum has suggested the possibility of a specific Disability Directive in relation to goods and services.

This Phase introduces as a priority the implementation of the UN Convention into practice in the policies of the various Member States. An emphasis on awareness raising and empowerment has also been introduced. The priorities and related actions will be formally presented in the biannual report on disability that the European Commission intends to publish in December 2007.

II.3. The Council of Europe *Disability Action Plan 2006 – 2015*

The Council of Europe *Disability Action Plan 2006 – 2015* seeks to translate the aims of the Council of Europe with regard to human rights, non-discrimination, equal opportunities, full citizenship and participation of people with disabilities, into a European policy framework on disability for the next decade.

This Action Plan aims to provide a comprehensive framework that is both flexible and adaptable in order to meet country-specific conditions. It is intended to serve as a roadmap for policy makers, to enable them to design, adjust, refocus and implement appropriate plans, programmes and innovative strategies. It has fifteen action lines including:

- Participation in public and political life
- Participation in cultural life
- Access to information and communications
- Equal access to education
- Employment and vocational guidance
- A Barrier free built environment
- Accessible transport
- Health Care
- Comprehensive rehabilitation
- Social protection
- Legal protection
- Protection against violence and abuse
- Awareness raising.

Starting points for any National Disability Strategy are the anti-discriminatory and human rights frameworks based on independence, freedom of choice and the quality of life of people with disabilities, and awareness raising about disability as a part of human diversity. The Council of Europe *Disability Action Plan* has a broad scope and holistic approach, encompassing all key areas of the life of people with disabilities.

The CoE Action Plan also highlights the phenomenon of *multiple barriers or discrimination*. Women and girls with disabilities, people with disabilities in need of a high level of support, children and young people with disabilities, ageing people with disabilities and people with disabilities from minorities and migrant communities have a higher risk of exclusion, and generally have lower levels of participation in society than other disabled people. The above-mentioned specific groups of people with disabilities require a cross-cutting response to ensure their inclusion in society.

III. Trends, tendencies and prevailing concepts

III.1. Holistic approach to disability

Disability is increasingly considered as a complex 'package' of factors and elements that relate to various aspects of the person and of society. Consequently, disability policy-making at a macro-level, as well as rehabilitation at a micro-level, should complement each other in improving the lived experience of people with disabilities. Thus, the identified needs of an individual must be addressed across a range of different policy domains and/or multi-disciplinary interventions.

The holistic concept of disability requires policymakers to find ways to coordinate measures and mechanisms across the policy domains impacting on disability, including health, social services, employment, education, transport, sports and leisure. A major obstacle to the smooth coordination of policy is the so-called '*silo*' thinking by different stakeholders/departments. For instance, the Department of Labour does not address health and social gain, although improvement of health could be an important precondition to getting people back to work. Similarly, the funding of special education by the Department of Education does not always include transition services to the labour market. The Education Ministry is responsible for qualifications, but it is the Department of Labour that is responsible for employment and it is often not clear which Department of Government is responsible for integration into society. Restoring a person who has acquired an impairment to an active citizenship role can require comprehensive rehabilitation services but often different responsibilities for funding create fragmentation in provision.

There are a number of structures and processes that can be introduced in order to achieve a coordinated, continuum of provision for people with disabilities, ranging from a single department responsible for all disability-related issues, through an integrated cross-sectoral National Disability Strategy coordinated by a Designated State Agency, to a multi-sectoral approach based on a set of common criteria and goals. Some countries have introduced one-stop shops for information, advice and advocacy with cross-sectoral scope, while others have opted for the introduction of case-management services to assist people in obtaining the services specified in their individual plan.

In terms of rehabilitation, the holistic approach means that people with disabilities need multi-faceted, planned and coordinated assistance in order to achieve their goals. The two key requirements in this respect are 'person centred' service packages and 'partnerships' between various service providers and actors in society that play a role in achieving the goals of the person with a disability.

III.2. Mainstreaming

A commonly used definition of mainstreaming stipulates that 'all policies, programmes and activities should incorporate a disability perspective, so no specific/special actions are needed towards people with disabilities'. The definition also states that all groups in society should be aware of disability issues and be prepared to invest efforts and resources to integrate people with disabilities. This definition is very much in line with the social model of disability and focuses on equality of opportunities and concepts such as partnership and participation.

However, in practice, this interpretation of mainstreaming can include serious risks. Some groups with severe/complex disabilities still need specific policy measures or interventions. These groups need some level of support in order to enable them to fully benefit from 'equal opportunities in society'. Moreover, policy makers in some countries have abused the concept of mainstreaming to justify reduced financing for disability-specific measures and support services.

Based on these experiences, the European Commission along with a large majority of other stakeholder groups at European level now use a modified definition, stating that mainstreaming of disability should be complemented with specific actions/programmes which foster the development of disability-specific expertise and solutions. This interpretation of the mainstreaming concept is also more in-line with the International Classification of Functioning, whereby the 'biopsychosocial model' describes disability as a dynamic interaction between impairment on the one hand, and environmental and personal factors on the other hand.

In relation to *employment*, the legal background for the principle of mainstreaming policies lies in the EU Directive against discrimination which prohibits discrimination in employment and occupation on the grounds of religion and belief, disability, age and sexual orientation. The Directive prohibits any discrimination - be it direct or indirect on all grounds mentioned - in employment and occupation, defined as access to employment, self-employment and occupation, vocational guidance and training, employment and working conditions including dismissal and pay, and membership of organisations. Employers are obliged to accommodate the needs of people with disabilities to ensure that they have an equal opportunity to compete in the labour market.

Mainstreaming of *service provision* to people with disabilities implies that the clients should no longer have to attend a special centre to receive rehabilitation services, but that services and supports are provided to people with disabilities to enable them to participate without problems in regular 'mainstream' activities such as schools, employment, independent living, etc. Consequently, these services now need to be much more focused, community-based and specific. For many service providers used to offering complete programmes to service-users on their own premises, this development requires a huge change of mentality, approach and internal organisation.

III.3 Community-based rehabilitation services

Community-based rehabilitation (CBR) is a strategy within general community development. It concerns the equalisation of opportunities and social inclusion of all people with disabilities within the local community. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organisations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services.

Community action for CBR is often initiated from outside the community, such as by Ministries or NGOs. Following initial discussions, it is the community which then decides whether CBR will become part of its ongoing community development activities. Various partners in the community, such as a community development committee, organisations of people with disabilities and other non-governmental organisations can provide leadership and take responsibility for the programme. Once a community chooses to initiate a CBR programme, a programme management team provides the necessary support, including training, access to referral services and the mobilisation of resources.

The main objective of CBR is to ensure that people with disabilities are able to maximize their physical and mental abilities, to access regular services and opportunities, and to become active contributors to the community and society at large. It aims to activate communities to promote and protect the human rights of people with disabilities through changes within the community, for example, by removing barriers to participation.

National policies and supports, along with intermediate level management and local government involvement, are essential elements of CBR programmes. The manner in which communities are linked to the national level varies, depending on the administrative structure of the country and the particular Ministry that promotes and supports the CBR Programme. In all situations, however, national policies are needed to guide the overall priorities and planning of a CBR programme. National level coordination and allocation of adequate resources are other elements identified with successful CBR programmes

In CBR, a trans-sectoral collaboration is essential to support the community, address the individual needs of people with disabilities, and strengthen the role of NGOs. In addition to collaboration between government ministries, cooperation is also needed between the statutory sector, non-governmental organisations and the private sector. Partnership is needed between the community and referral services at local and intermediate levels, and also between the various referral services at local, intermediate and national levels.

III.4. Ageing and disability

The number of ageing people and disabled ageing people in Europe is increasing rapidly. In the coming years, it is estimated that across Europe, about 15 million elderly will acquire some form of disability, while about 10 million people with a (current) disability will become elderly. The percentage of disabled people among age groups increases with age, as people tend to acquire disabilities when getting older in terms of reduced mobility, chronic illness, etc. Also, in terms of the WHO International Classification of Functioning – the leading system to define disability nowadays – ‘ageing is disabling’, since the functional capacity of a person directly impacts on his or her level of participation.

The ‘double ageing phenomenon’ (both parents/caretakers and persons with disabilities) raises even bigger challenges as some parents/caretakers might not be able to continue to fulfil their supportive role. Models of transition from family to professional caring will be needed for people with intellectual disabilities for whom the supportive role is often shared between parents and professional service providers.

This development poses several challenges for policymakers but also for other stakeholders in the disability sector, such as service providers. Firstly, the combination of people with disabilities living longer coupled with elderly people becoming disabled due to ageing will drastically increase the demand for services. Moreover, the number of clients in the higher age categories will increase and require more intensive services and different approaches/methodologies.

Despite the lack of reliable figures and statistics, the growing number of ageing disabled people can be predicted, although this phenomenon does not happen overnight. As such, any disability strategy should anticipate such developments and include answers to these challenges.

In general, three main strategies can be identified:

- Keep people with disabilities in their current services, and adapt these services to better fit their changing needs. This option may pose problems, as buildings might be difficult to alter, other service-users may not want the service to change radically, and it would be costly.
- Develop new specialist services for older people with disabilities. This strategy requires a great deal of expertise, staff training, and additional sources of funding.
- Move people with disabilities that grow older into mainstream services for elderly people, where they are surrounded by people of similar age. This solution is cost-effective, but there is the risk that the service would be inadequate for elderly disabled people, and that they would be ignored by other service users.

A particular point of attention in this context is the need to develop laws and policies promoting and recognizing supported decision-making in cases where older people with disabilities, life-long dependency and/or intellectual disabilities have severe difficulties in making independent choices and decisions, and to provide services and systems of support to facilitate assisted decision-making.

It is also important to recognise that the relationship between ageing and disability begins at around the age of fifty, and that the number of workers who are exiting the workforce as a result of disability and chronic illness is increasing year on year. The response to this phenomenon is to enhance workplaces through health promotion and to put in place Disability Management and return to work services. These are an essential element of a National Disability Strategy, as the burden of social protection should not to become unsustainable.

III.5. User-Involvement and User-Centredness

During the last decades, the position of users has become much stronger in the process of service delivery. The development of specific legislation in several countries, strong efforts of the disability movement like the Madrid Declaration adopted by EDF (2002), the recent adoption of the UN Convention on the Rights of People with Disabilities and the introduction of the new classification ICF with particular emphasis on participation, has boosted the worldwide recognition of the position of people with disabilities as equal citizens in society.

Furthermore, changing policies, the pressure on financial resources and the growing influence of the clients themselves, e.g. via personal budgets, will lead to a much more active and responsible role of the service-users. Therefore policy-makers, as well as service-providers, should take the motto of the European Year of People with Disabilities 2003, "Nothing about Us without Us", very seriously. Finally, 'user-centred' approaches prioritize the principle of subsidiarity. This principle specifies that it is wrong for a 'superior body' to make decisions on behalf of those who are already well qualified to make those decisions for themselves. In effect, subsidiarity enshrines the principle that users are the experts on their own condition and are therefore best placed to come to conclusions about appropriate solutions for themselves.

From the viewpoint of service-providers, the principle of user involvement combines both the crucial ethical dimension of "Nothing about Us without Us" and a business rationale. The latter reflects the changing sectoral context which increasingly requires service providers to consider service users as consumers. The participation of service-users in strategy development and management structures of service providers should be optimised. The concept of service users as partners in service delivery at all levels will be a key element of any successful management strategy. Moreover, coalitions with service-user organisations will be essential in convincing policy makers to ensure a sufficient availability of high quality services.

'User-centred' approaches empower the user as a 'customer'. Within the health and social care sector, the majority of services are not purchased directly by users or their families, but are delivered to the user on behalf of a funding agency. This can be a significant disempowering factor from the perspective of the user. 'User-centred' approaches set out to balance the requirements of funders with the responsibility to value the user as a customer.

These approaches place the person with a disability in control of their own resources, for example, through personal budgets or direct payments, so that they can genuinely purchase services that they need, when and where they wish. At the level of policy-making, people with disabilities should be represented at governmental level and on all key committees and boards that have policymaking and decision making roles within the system. Finally, people with disabilities have a key role in setting policies and standards and monitoring conformance with those standards

The key condition for user-involvement at all levels is that people with disabilities are in a position to make 'informed choices'. This requires, above all, that they are empowered and have both sufficient information and analytical capacity to play their role as decision-maker and/or advisor.

III.6. Justification of services

Service-users and society in general, and policy-makers and funders in particular, become increasingly demanding and critical of the provision of services to people with disabilities. On the one hand, this is due to decreasing financial resources for social welfare while an increasing number of people are entitled to services. On the other hand, the growing concept of citizenship stimulates public opinion, and service-users expect tangible results and a cost-effective use of tax payers' money.

One way to address this is to introduce the concept of competition between service-providers. Competition has become a reality in a number of Member States and is likely to further increase. This trend is reflected throughout Europe, by tendering of services, direct allocation of budgets to service-users, and the related entering of commercial service providers into the rehabilitation market. The concept is new to organisations that traditionally operated in a 'soft' environment of not-for-profit service providers, which focused, for a long time, on their existence and objectives, rather than on outcomes and cost-effectiveness.

Thus, service providers are increasingly coming under pressure to demonstrate that their services add value to both the individual and society. This can be done, primarily, by measuring the outcomes of these services in economic terms, e.g. people with disabilities entering the labour market, or in terms of well-being, increased independence, participation, social cohesion and other 'soft' indicators. The focus is not so much on what is done and how it is done but on the impact and results for society and the persons with disabilities (and their families).

In summary, it comes down to ensuring that the 'actually attributed value' corresponds to the 'perceived' value in the eyes of all stakeholders in the field of disability. This means satisfying the needs of clients and the expectations from stakeholders, and requires an analysis and understanding of these expectations. One way to demonstrate added value is to use the comparison with alternative solutions (including doing nothing), which is used to prove that 'rehabilitation pays'.

In addition to proving that we do the 'right' things, service providers have to prove that they 'do things right' in terms of providing value for money. On the one hand, this relates to managing resources well through cost-effective processes. On the other hand, it requires emphasising the quality of the service on the basis of measured results and outcomes. Service providers should not defend their historical position and interests, but play a constructive role in the debate on these new developments. In doing so, they can take into account the concerns of society while maintaining a high quality service-provision that starts from the interests of people with disabilities.

Outcome measurement, as used in some other (economic) sectors, has not been systematically developed in the "rehabilitation industry." Indicators that are often used include the improvement in the quality of life, better health conditions, a more independent situation, less care needed after the service, a return to full or part-time work, less or no benefits in the long run, and tax revenues instead of welfare costs, etc. The most effective way of justifying rehabilitation services is a multiple approach: using the outcomes of economic evaluation studies, and cost-benefit analyses.

III.7. Quality of disability-related services

Quality and quality assurance of disability-related social services have gained importance as a consequence of an increased focus on cost-effectiveness, the growing competition between service-providers, and the trans-national dimension of services. Greater competition and the liberalisation of the market for social services to people with disabilities can result in the establishment of many new service providers that often lack experience and specific expertise. Moreover, tendering, which is increasingly used to allocate contracts to service providers, often focuses on price rather than quality of services, and can threaten the sustainability of the service provider.

As a result of increased transnational service provision, or the “Europeanization” of the rehabilitation market, people with disabilities will be entitled to obtain services in another country, professionals will be able to move across the borders to continue their careers, and service providers will be entitled to set up new activities in other countries without restrictions.

A quality framework at European level could provide a guarantee to service users and purchasers of services, and at the same times allow “good” service providers to distinguish themselves from their competitors. Moreover, a European quality framework could contribute to increasing the quality of services to people with disabilities in some new Member States.

It has become increasingly clear that these developments require a European approach towards quality. However, regulating services to people with disabilities is the competence of the Member States, and the national legal, economic, cultural and social contexts differ considerably. Consequently, it is neither feasible nor desirable to operate detailed, specific and prescriptive minimum quality standards at European level (quality assurance approach).

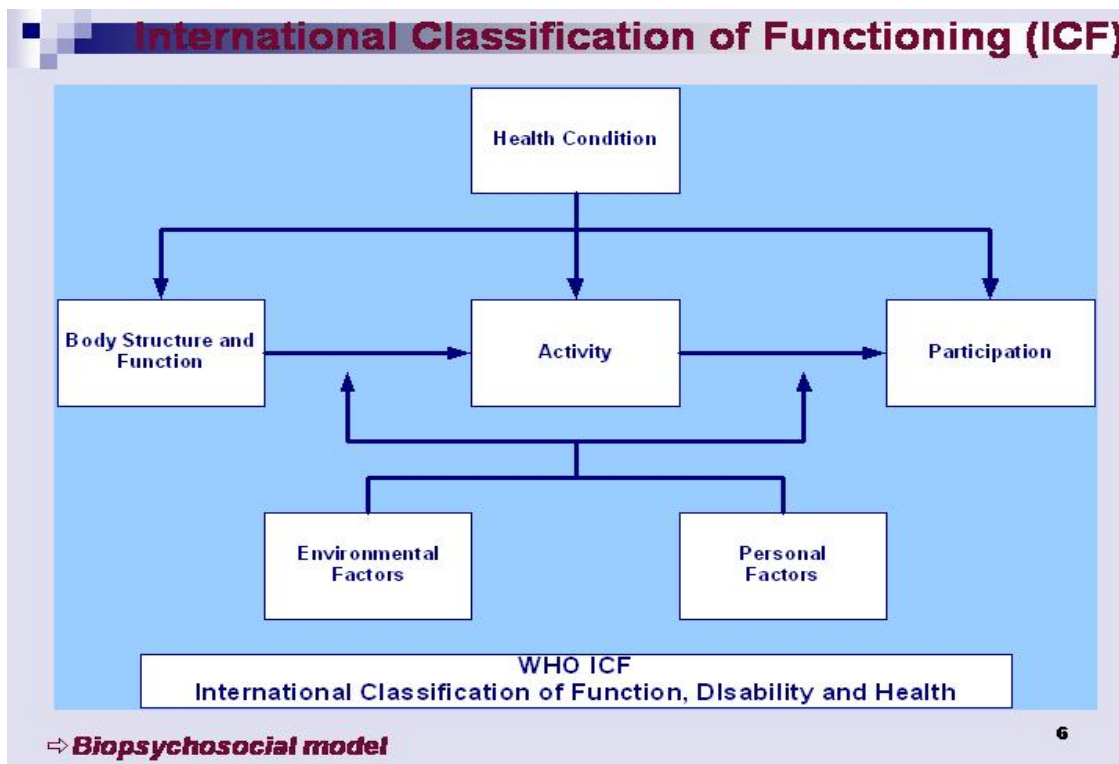
A solution could be offered by a total quality management approach that starts from values and principles of excellence that are widely agreed by all sectoral stakeholders throughout Europe. Such an approach would offer sufficient flexibility to overcome the different national contexts, as compliance with the principles and their indicators can be achieved in various ways.

It should be mentioned, in this respect, that there is already one European quality system in place which is sector specific and operated by the main European stakeholders in the field of disability: the *European Quality in Rehabilitation Mark (EQRM)*. Organisations of disabled people, service providers, policymakers, social partners, insurers and funders have agreed on the following Nine Principles of Excellence¹ for service-provision: Leadership, Person-centredness, Rights, Partnership, Ethics, Participation, Comprehensiveness, Results-orientation and Continuous improvement.

¹ Detailed definitions of Nine Principles of Excellence and their indicators can be found on www.epr.eu

III.8 International Classification of Functioning, Disability and Health

The *International Classification of Functioning, Disability and Health*, known more commonly as ICF, is the conceptual basis for the definition, measurement and policy formulations for health and disability. Policy development in these sectors requires valid and reliable population data on functional status. Legislative and regulatory definitions of disability need to be consistent and grounded in a single coherent model of the disability creation process. Whether it is devising eligibility criteria for disability pensions, developing regulations for access to assistive technology, or mandating housing or transportation policy that accommodates individuals with mobility, sensory or intellectual disability, ICF can provide the framework for comprehensive and coherent disability-related social policy.



As the diagram above indicates, ICF views disability and functioning as outcomes of interactions between *health conditions* (diseases, disorders and injuries) and *contextual factors*. Among contextual factors are external *environmental factors* (for example, social attitudes, architectural characteristics, legal and social structures, as well as climate, terrain and so forth); and internal *personal factors*, which include gender, age, coping styles, social background, education, profession, past and current experience, overall behaviour pattern, character and other factors that influence how disability is experienced by the individual.

The diagram identifies the three levels of human functioning classified by ICF, and 'disability' involves reduced function at one or more of these levels:

- Functioning at the level of body or body part;
- The functioning of the whole person, reflected in 'activities' that the person can perform;
- The functioning of the whole person in a social context, which is reflected in the participation of a person in the society.

III.9 Employment for people with disabilities

Employment of people with disabilities has been a priority area of EU disability policies for several years. It is a major instrument in the drive towards social inclusion and independent living, and is moreover essential for achieving the objectives of the Lisbon Strategy. Employment is considered as one of the main pathways to (re)integration and participation in society, as it provides status, financial means to be independent and in control, self-esteem, satisfaction and many social contacts to people with disabilities.

Yet, progress has been slow and the unemployment levels of people with disabilities remain high. In line with the philosophy of maximising the potential of each person with a disability, solutions for integration into the open labour market should be prioritised. Improved quality and access to vocational training and rehabilitation services for people with disabilities are certainly issues that deserve more attention in this employment debate. Another new area that needs further discussion relates to 'Disability Management', a rather new concept that addresses employers, rather than the individual, to remove barriers to employment. Finally, strategies to increase job retention via empowerment of the persons with disabilities should be part of every policy debate.

Following the concept of mainstreaming, the entire European Employment Strategy (EES) relates to people with disabilities. However, all parties involved recognise that a continuous pro-active approach is still needed in order to ensure that EES measures effectively impact on the employment rates of people with disabilities. Legal action needs to be complemented with political action, as well as with professional expertise on how to get and keep people with disabilities at work.

European research has demonstrated that both employers and service providers share the view that their efforts to (re)integrate people with disabilities into the open labour market should be facilitated by the public authorities and policy makers. The following list of suggestions and recommendations was formulated by these stakeholder groups in the different countries.

- There must be clear support from Governments. Governments should clearly state their policy in terms of equal treatment of people with disabilities in the open labour market and support its implementation with adequate information campaigns and financial support to service providers as well as other training and employment services.
- Support should be based on a long-term policy with no diminution of effort as Governments come and go.
- Laws against the dismissal of people with disabilities should not be an obstacle to hiring. People with disabilities should have the same terms and conditions as other employees.
- The threshold for people with disabilities to the open labour market should be lowered by entitling them to return to their disability pensions and benefits in the event that they fail to retain employment.

Many European Member States now have a focus on non-discriminative legislation. Others also operate negative incentives and regulations in the form of quotas and sanctions. While the debate about the impact of quotas is ongoing, it is clear that those countries that operate them are very committed to retaining them.

IV. International Case Studies

In order to put the international trends described above into context, three national case studies are presented below. Each example has unique characteristics that arise from the social, political, cultural and economic conditions existing within the jurisdiction but each case study also reflects the influence of different global factors. The Netherlands has been chosen because it demonstrates the problems that can arise when the burden of social protection becomes unsustainable. What is most interesting about the Dutch approach is that a set of radical market-based strategies was introduced that increased the control of employers and people with disabilities over resources, and fostered open competition amongst service providers. The Norwegian case study is an example of how cycles of policy development can build on each other to achieve continued improvement in the way in which disability is disseminated. It is also a good example of a State-led initiative which has increasingly become driven by the user organisations. The Irish case study is an example of an initially user-led initiative which has increasingly become State-led where strategy has been legislated. Both Norway and Ireland have relied heavily on international policy instruments and guidelines.

IV.1 The Netherlands

Introduction

The Netherlands has a long tradition of taking measures to reduce high sickness absence levels and decreasing the number of persons on disability benefits. In the 1990s, the term “Dutch disease” became synonymous with the utilisation of disability benefits to exit older employees and redundant workers from the workforce. This was particularly the case in restructured economic sectors such as mining, shipyards and textiles. As a result, sickness absence had reached over 8% in terms of days lost and the number of people receiving full or partial disability benefits grew to almost 1 million (about 12% of the insured population).

In the early 1990s, the sustainability of the social security system became a major concern, and from 1992 onwards various measures were taken to revise benefit schemes, the institutional context and the responsibilities of key actors. Initially, the continuously increasing costs of social security was the core argument in favour of reforms. However, at later stages in the process, the “labour market argument” gained weight. This followed the logic that as those who were dependent on disability pensions and benefits, i.e. economically inactive, increased, the number of people available for work reduced. As a result, a range of new policies aimed at stimulating people with reduced work capacities to remain in employment in order to fill the vacancies that were increasing rapidly, due to ageing, among other reasons.

Thus, where initial measures focussed on legal and administrative actions, such as reducing benefit levels, the introduction of stricter eligibility criteria and revised assessment methodologies, later reforms concentrated on a redistribution of responsibilities amongst the actors, the introduction of financial incentives for employers, the privatisation of rehabilitation service provision, and the introduction of more customised rehabilitation and employment services for persons with disabilities to assist them in (re-) entering the labour market.

The Change Process

Consultation of social partners

In the Netherlands, reforms in policy are strongly influenced by the institutional context of the Dutch system of industrial relations. This system is characterized by cooperation of Government, labour unions and employers' organisations. Social partners act as the main advisory body to the Government on social and economic policy matters. This was also the case in the reform of social security and disability policy. Many, but not all, of the resulting changes were facilitated by the commitment of social partners. In addition, social partners periodically take the initiative and propose common policy reform, which is often accepted by government and used in proposals for policy revision.

A core actor in this process is the Ministry of Social Affairs and Employment. Some of the themes that were subject to consultation included mechanisms to reduce the sickness and disability benefit payments and increase labour market participation. Consequently, policies focusing on people with disabilities who were never in the labour market, due to age or long-term unemployment, received less attention, as the strong focus turned towards those in employment who became temporarily or permanently disabled.

Parliamentary investigation and multidisciplinary advisory committees

An important trigger for the reforms was a parliamentary investigation ("Buurmeijer Committee") into the growth of disability benefits and possible mismanagement in the social security system carried out in the early 1990s. Based on the findings of this investigation, a major reform proposed the exclusion of social partners from steering boards of the social insurance administrations, which were instead brought under the control of the government. Other changes proposed by the committee focused on the institutional and administrative spheres, including rehabilitation policies.

Ten years later, the increasing number of individuals entering the disability benefit net due to psychological or mental health problems, resulted in the Government setting up another committee to address these issues ("Donner Committee", 2000). Initially, the committee only consisted of experts from the tri-partite background (i.e. political parties, trade unions and employers' organisations). It made recommendations for the improvement in systems of prevention, care, treatment, and reintegration in case of sickness absence due to mental health complaints. A follow up committee, which also included representatives from health care professionals, patients, rehabilitation providers, etc. further analysed the problems and proposed further reforms.

Government designs, consults, prepares and implements

This committee advised that only 'fully and permanently' disabled individuals should be eligible for disability benefit payments. Moreover, it placed a responsibility on employers to find or create an appropriate job role for both partially and temporarily disabled employees. In parallel, the employee should play an active role in his/her reintegration and be obliged to accept the offer of a different, suitable job placement. The committee

also produced guidelines for managing sickness absence and disability due to psychological problems.

The proposals of both committees were translated into legislation which was eventually accepted by the social partner's consultation body with some critical comments and it came into force 2006.

Other consultative bodies

During the fifteen years it took to implement reforms in the Dutch system other bodies have also had an advisory role. In particular, the SER (Social and Economic Council) is the main advisory body to the Dutch Government and Parliament on national and international social and economic policy. It is wholly independent and advises the Government, upon request or at its own initiative, on all major social and economic issues. It comprises of representatives from central labour unions and employers' organisations, as well as independent members, e.g. researchers and scientists. Its advice is not binding but is usually very influential, especially in the case where the advice is unanimous.

Since 2002, it has been possible for the Council for Work and Income (RWI) to be consulted or to give proposals in the area of disability and employment. This council was set up to act as an independent advisory body to the Minister of Social Affairs and Employment on the policy relating to work and income. Employers' organisations, labour unions and municipalities are represented.

At the end of the nineties the Ministry of Social Affairs and Employment took the initiative to form a national commission to promote the employability of people with disability. A major goal of the commission was to change the image of people with disabilities, especially among employers and professionals. The work of the commission consisted of public awareness campaigns, the dissemination of good practices and the development of tools. It was chaired by both a Captain of industry and a senior representative of the Unions and functioned until April 2007 under different names. The last commission was called the Commission on the Working Perspective. From 2007 the work of the commission is being continued by the Dutch Employers forum.

Finally, the Council for the Chronically Sick and Handicapped (CG-Raad) is the central council representing associations for people with disabilities. It also provides advice, but does not have the official status or organisation of the two previously mentioned organisations. The Council has played a relatively small role in the process of change to the social security systems.

Thus, it may be concluded that, in the Netherlands, the reform process was initiated by Government as a result of financial and employment concerns, supported by extended consultations and public discussions. The results of the implementation and wider impact are subsequently monitored and evaluated by the Government, on the request of Parliament.

The Strategy

Core dimensions

The main focus of reforms in Dutch disability policies is the working age population, and in particular, workers with temporary or permanent health restrictions or impairments. Comparatively less attention has been paid to policies for job seekers with disabilities who have no employment history whatsoever. Consequently, the core actors in the new regulations are the employer, employee and (former) employee receiving a disability benefit.

The main principles of recent reforms and current policies are:

- a. Increased financial incentives and labour reintegration responsibilities for employers;
- b. Financial incentives and responsibilities for employees and benefit recipients (aimed at reducing the attractiveness of, and/or dependency on long-term benefits);
- c. The privatization of, and the introduction of competition in, service provision in the field of occupational health, vocational rehabilitation and employment services;
- d. More flexibility, less bureaucracy, and room for experimentation with new instruments and supporting structures for promoting the employment of people with health or functional restrictions.

In addition, some supportive or facilitating legal changes were made in related policy areas to counterbalance negative side effects of the reforms.

The first principle, more responsibility for the employer, reflects the viewpoint and research findings that sickness absence can substantially be affected by the employer's personnel and disability policy.

Employers should take responsibility for prevention and reintegration, instead of waiting for actions or decisions by physicians, social security agencies or rehabilitation centres. Moreover, as inflow into the disability benefit scheme is usually preceded by long-term sickness absence, early intervention by the employer is considered the best strategy to avoid disability benefit claims.

The second principle is reflected in the strengthening of the active role of the employee in recovery, rehabilitation and work resumption. During recovery, the worker must accept any suitable work offered by the employer that fits to his/her restricted capacities. Moreover, for the second year of work, incapacity income replacement rates have been lowered to 70%.

Employer, employee and prevention of disability (benefit dependency)

The consequences of the increased responsibilities for employers and employees are reflected in the following regulations and obligations:

a. At a financial level:

In 1996, the first step was made to make employers and employees aware of the costs of sickness absence. A period of *continued wage payment by the employer* for absent workers was introduced, initially for 2 weeks in the case of small employers and 6 weeks for larger enterprises. The effect of this measure was a positive drop of 20% in days lost. As a result, the wage payment period was extended in 1998 to one year. Since 2004, this has been extended to 104 weeks. The aim is to give incentives to employers to make every effort to redeploy sick and absent employees internally. The employer may insure against this risk with private insurance companies.

b. At a procedural level:

The *Improved Gatekeeper Act* (WVP, 2004) aims to stimulate re-integration, preferably in the first year of sickness absence. In the case of sickness or injury, the employer and employee must have regular contact. Further, the occupational health service (OHS) or the occupational physician (OP) is required to make a “problem analysis” within six weeks after the onset of work incapacity. In the 13th week, the employer and employee must agree on a Return to Work action plan. If work incapacity continues after this point, the employer, employee and the OHS/OP stay in regular contact to consider opportunities for a full or partial work resumption, with or without temporary or permanent adaptations in tasks, working hours, etc. If work incapacity continues and return to work is clearly not possible, the employee can apply for disability benefit payments after two years. The granting of a pension depends on a judgement by the social security agency as to whether or not the employer and employee invested sufficient effort in the work resumption process.

Support from private service providers

A third core dimension of disability policies in the Netherlands involves the increased role of private service providers in the process of return to work and rehabilitation. Apart from the role played by OHSs, labour reintegration services (RIBs) have also flourished. These enterprises provide various services to employers in order to re-integrate long-term work incapacitated employees back into the company or to redeploy them to another employer. They also operate on behalf of the social insurance agency (UWV) and the municipalities.

In 2002, the SUWI or ‘Implementation Structure for Work and Income’ came into force. This marked the end of the direct involvement of social partners in the administration of social security and labour market implementation bodies. Since then, both UWV and the municipalities have been responsible for the integration of benefit recipients, (the UWV for unemployment and disability recipients, and the municipalities for social welfare recipients). However, these bodies are not allowed to implement services themselves. Both, therefore, take on the role of purchaser and apply tender procedures to stimulate provider competition, as stipulated by law. Labour reintegration services may provide various products like assessments, training, job search, placement, case management, etc. Furthermore, payment by the social security agencies and the municipality follow the principle of “no cure, less pay”.

Personal budget: a new approach in providing services to assist people to leave the benefit system

Under this scheme a person may apply for a *personal labour reintegration budget*, which gives him/her the responsibility, tools and budget to acquire services for empowerment and return to employment. The drivers behind this development were the strong support of client organisations, academics and labour unions, the modest success in terms of placement rates of existing programmes, and the fact that some clients were considered to be too dependent on procedures in the sometimes understaffed administrations.

After a number of pilot projects, the personal budget has been added to the repertoire of measures and facilities to stimulate return to the labour market. When applying for a budget, the client has to develop and submit a 'personal reintegration action plan', approved by an OH physician, describing his/her motivation, target job, as well as the services needed to improve his/her position on the labour market.

In 2004, the programme was rolled out nationwide. Moreover, it has become available to other categories of clients, including the unemployed and social assistance recipients. The programme, called "IRO" (literally: "Individual Reintegration Agreement"), has been quite popular, with 39,000 budgets provided by April 2006 and only 2.4 % of requests have been denied.

Compared to the clients making use of the "regular" rehabilitation and re-employment services, where the administrators make the individual plan and negotiate with service providers, there are no differences in age and gender distribution, although users of this budget scheme tend to have a higher level of education (i.e. 43% of unemployment and 25% disability benefit recipients).

Evaluations demonstrate that the costs of the scheme are about 10 – 40% higher than expenditures per client in regular programmes. The average cost of a personal budget is €4425 (VAT excluded) and the maximum available is €5000 per voucher. But placement rates in open labour market employment are 20% - 80% higher than in the regular programmes.

Clients of an IRO are also more satisfied with the assistance of the service providers compared to clients of 'regular' return to work programmes. The major advantage they identify is that the IRO is more 'tailormade' and provides them with more personal assistance from labour reintegration services.

Supportive legislation on related areas

In order to support the implementation of reforms in the sickness and disability programmes, or to improve negative side effects, some additional legislation has been introduced. From an employers' perspective, the following regulations have been put in place:

- On the basis of the Working Conditions Act, whereby every employer is obliged to contract an *occupational health service* or occupational health expert. Occupational health legislation sets out a role for these professionals in prevention and return to work, both regarding medical and vocational interventions. Both the employer and the employee must receive support and advice on prevention of injuries, sickness and disability and advice on Return to Work (RTW) measures, like (temporary or permanent) adaptations of work site or working hours.
- In order to prevent employers making a selection of applicants for vacancies on the basis of health condition, *pre-employment medical examinations* are only permitted when the job requires specific health conditions or functional capacities. The Medical Examinations Act is designed to protect the personal and physical privacy of job applicants. It is only under the severest of restrictions that a medical examination is allowed in a personnel selection procedure, e.g. bus driver or airplane pilot. Since the act became operational, the number of pre-employment medical examinations has declined dramatically, but discussions about the effectiveness of the Medical Examination Act are ongoing.
- The high level of *job protection* for person with health restrictions is a long standing stipulation that affects employer behaviour. Dismissal due to, or during sickness absence, is not permitted unless the worker violates notification procedures or does not comply with the rules of recovery and work resumption. Since 1996, an employer is no longer obliged to continue paying wages if a worker does not cooperate.

Equal treatment

The Dutch Equal Treatment Act (1994) stipulates that no one in the Netherlands may be treated unequally. The grounds for this are the same as those incorporated in European law, which refer specifically to religion, belief, political opinion, race, sex, age, nationality, heterosexual or homosexual orientation and civil status. It was only in December 2003 that the Act was amended to include the equal treatment of disabled/chronically ill people.

Public authorities, businesses and institutions have to make necessary accommodations if they are so requested to do so by disabled or chronically ill people. However, the principle of disproportionate burden applies. Effective accommodations are defined as measures that are appropriate and necessary to enable participation in the life of society like any other citizen.

Social support for persons with disabilities

In January 2007, the Social Support Act (Wet Maatschappelijke Ondersteuning, WOK) was introduced in all municipalities in the Netherlands. This places policy responsibility for setting up social support upon the municipalities, who will be accountable to the citizens in the execution of this responsibility.

The Act targets social support in all sectors, including health services, social services and additional financial benefits. It has virtually eliminated a wide variety of rules and regulations regarding people with disabilities and the elderly.

The WOK is the result of an emphasis on individual responsibility in health care. In line with this principle, a new basic health insurance scheme has been introduced for the entire population. The WOK is part of this reform and introduces a new scheme for all Dutch citizens covering care and support in cases of protracted illness, invalidity or geriatric diseases.

The aim of the WOK is to promote and ensure the participation of all citizens in all sectors of society, whether or not with help from friends, family or acquaintances. This is a coherent policy in the field of social support and related areas, and can be considered to be a form of mainstreaming. The Ministry of Health, Welfare and Sport defines the framework within which each municipality can make its own policy, based on the composition and demands of its inhabitants.

Conclusions

The implementation of the new legislation and the assessment of the impact of new regulations and infrastructures have been the subject of monitoring and evaluation studies. Consequently, some evaluative information is available on the measures, implementation, outcomes, viewpoints and positions.

From the perspective of the original aims, i.e. reduction of public expenditures and higher activity rates in the labour market, it can be concluded that the targets have been reached. Sickness absence rates dropped from 5.4% to 4.0% after the most recent changes, which included the introduction of two years of wage payment and reintegration obligations on the employer. At the same time, in-flow into disability benefit schemes dropped within a year by 28%.

Evaluation studies have indicated that employers have become more aware of their responsibilities and are more active in retaining people in the workforce. Employee surveys also support this conclusion. Ultimately, employers are paying more attention to sickness management, return to work, temporary adaptations, and working conditions policy, in general.

But not improvements for all groups

In contrast, this drop in benefit dependency and increased labour force participation has not equally impacted on all schemes and categories of people with disabilities. Specifically, benefit programmes focusing on people without an employment relationship exhibit other trends.

In particular, the number of youngsters receiving a benefit under the Disability Insurance for Young Disabled Persons (Wajong), which is restricted to young people with disabilities over 17 years with disabilities, is growing rapidly. Further, the number of those with Wajong-status who are finding an appropriate job has not increased at all.

These young people face barriers in pursuing their studies and finding apprenticeships, as employers are reluctant to employ them or to offer them training. Recently, the Dutch Government initiated an investigation of the circumstances surrounding the Wajong-population in order to find new solutions and opportunities for them.

Another group who have not benefited are people who fall under the public sickness benefit scheme. Thus, the unemployed or those on temporary labour contracts have not shown an increase in employment outcomes either.

A new labour reintegration market

From an unprecedented increase in the number of service providers with the introduction of privatisation, the number of suppliers has decreased significantly as a result of competition, tendering and payment procedures. Services providing reintegration support now show placement rates which are minimally required by tendering bodies (social

security and municipalities). Further specialisation is also a feature of the market, with relatively small services focusing on labour reintegration of specific groups such as migrants, females, and people with mental health problems. These specialized services show higher success rates in placements, rather than with the larger mainstream agencies.

Continuing obstacles

There are still some major problems which need to be addressed within the Dutch system. In addition to the growth of younger people with disabilities on benefits, other key issues have not been addressed. In particular, attitudes to people with disabilities, in general, and the employment of persons with mental health problems are of continuing concern. The mind shift towards a positive attitude to the labour market competence and potential of people with disabilities is slow to change. Stereotypes and perceptions of employers, personnel managers, job site colleagues, physicians of people with disabilities are particularly difficult to influence.

While some studies have provided evidence that socio-medical experts, like occupational physicians and social insurance doctors, are now increasingly familiar with the competences and potential of people with disabilities, and that communication and cooperation between these professionals, clients and other service providers has improved, employers and supervisors still maintain a focus on a person's restrictions. Equally, treating physicians still need awareness and training in relation to the need to take employment into account when making a diagnosis, choosing treatments and defining recovery success.

People with mental health problems still experience severe difficulties in accessing the labour market, regardless of whether their problems are psychosomatic and less objectively detectable, such as burnout, stress, Chronic Fatigue Syndrome, or clearly psychiatric in nature. The majority of people experiencing these difficulties are still in receipt of a *full* disability benefit, meaning that they are still classified as having no functional or employable capacities.

The personal reintegration budget has proved to be a fruitful approach for such people. Nevertheless, (re-) employment rates are still comparatively low. Moreover, when still in employment, employees with these conditions experience an environment in which other people do not know how to deal with them. A substantial majority of employers and supervisors who responded to a recent survey indicated that they experience a high psychological barrier to taking the initiative and making contact with an employee listed as sick due to mental health problems.

Further, the non-work environment of people with disabilities has received the same level of attention in the Netherlands, and thus outside of the employment sphere, many barriers still exist. People with disabilities in search of appropriate care, education, training or first time employment still, therefore, meet a personal environment, in terms of relatives and friends, which is often not acquainted with empowerment and which still perpetuates the "victim role".

Some moderate recommendations

When comparing the Dutch disability strategy with those in other countries, what becomes clear is not only the amount of legal and organisational changes that have been implemented, but also the paradigm shift in relation to the responsibilities of employers. On closer examination of these changes, it is possible to see the Dutch culture of social dialogue and consensus not only in the solutions which have been put forward, but also in the way in which the problems originally emerged.

Moreover, it is important to note that part of the success of the final reforms was facilitated by the favourable economic cycle and the ageing of the working age population. These factors provided a growth in vacancies and consequently, employers, starting with larger firms, became more open to diversity and age conscious personnel policy.

The Dutch experience demonstrates that increasing employers' responsibilities and those of the employee can create an atmosphere in which long-term work incapacity can be avoided. De-medicalisation, i.e. reducing the role and the weight of medical aspects in the area of return to work but not in the area of treatment, and increasing the role of non-medical interventions and actors, are some important features of this shift. Due to this shift the focus has changed from 'incapacity' to 'capacity'.

Furthermore, innovation in unorthodox measures such as giving more power to the client (via a personal budget) and reducing the role of the "traditional" service providers, e.g. social insurance agencies and public employment services, has proved to be positive.

These positive impressions are only partly reflected in cost benefit analyses, which are difficult to apply in these circumstances, particularly in the context of so many changes. It is also important to emphasise that the process of piloting, learning, solving problems, meeting new challenges, and formalising in new regulations and business practices, takes a lot of time. It has, therefore, taken a period of at least fifteen years to make this shift in policies accepted and implemented in Dutch society.

IV.2 Norway

Introduction

Norway has had three National Disabilities Strategies since 1990, the first of which ran from 1990 – 1993, the second from 1994 – 1997 and the last one from 1998 – 2002. Currently, therefore, there is not a National Disability Strategy in place. During the period in which these strategies were underway, a number of Governmental White Papers were produced for the Storting (Parliament) and several statutory reports (NOU) were also published.

Norway is a small country with a population of about 4.5 million (2006), and is considered to be one of Europe's most egalitarian societies. Traditionally, there has been close cooperation between the different classes of society, and this is certainly true since the end of World War II. In relation to the issue of disability, there has always been a strong link between NGOs representing the disability sector and political parties, especially the Labour party which is the main party in Norway.

Since the 1960s, there has been a focus on integration and normalisation in Norwegian society. Issues such as de-institutionalising the disability services, civil rights and user participation have been addressed, and in 1969, the Norwegian State Council on Disability was established. In 1979, the Government started a committee for Contact and Negotiations with the main NGOs for people with disabilities.

As a result, an important dimension in all three National Disabilities Strategies is the strong focus on User Participation as the principle means of ensuring that people with disabilities have a strong voice in the policymaking process in Norway. In a number of decisions and projects, there has even been full user control, whereby NGOs held a majority of seats on the directorial boards.

From this perspective it is possible to conclude that the progressive forces leading to the three National Disabilities Strategies came from NGOs representing the disability sector, the Public Council for the Disabled, and progressive politicians, Ministers and their administrators in the relevant Ministries.

The Change Process

The United Nations (UN) declared full participation and equality of status as the main objectives for the UN decade for people with disabilities (1980 – 1990), with 1981 being the International Year of People with Disabilities. These declarations inspired NGOs in Norway and the progressive forces among politicians and bureaucrats to take action. Thus, the Norwegian National Disabilities Strategies can be seen as a response to these UN initiatives.

In June 1993, based on a proposal from the Council for the Disabled, the Norwegian Government established a Committee of State Secretaries with the aim of strengthening the common policy for people with disabilities and reinforcing cooperation between relevant Ministries. This Committee took a lead role in promoting the concept of National Disability Strategies.

Thus, NGOs representing the disability sector were invited by the Ministry of Social Welfare to suggest areas where measures for improvement in living conditions could be implemented. Twenty-two NGOs responded to the invitation and proposed a maximum of five areas to be prioritised in the first National Disability Strategy (1990 – 1993). Subsequently, fifty-one NGOs contributed to the target areas for the second period from 1994 – 1997.

The priority areas that emerged for the first National Disability Strategy (1990 – 1993) were:

1. Health /social services with a focus on respite, support, contact and information.
2. Housing programs, particularly suitable houses for different life situations
3. An increased focus on education for children with disabilities, including extra curricular activities and special pedagogic programmes.
4. Information about disabilities/diagnosis for professionals, administrators, politicians, parents and information about the rights of people with disabilities.

The priority areas included in the second National Disability Strategy (1994 – 1997) were:

1. Personal economy, i.e. social security benefits and the economics of NGOs.
2. Health /social services with a focus on respite, support and social contact.
3. An increased focus on the education of children with disabilities, including extra curricular activities and special pedagogic programmes for children.
4. Information about disabilities/diagnosis to professionals, bureaucrats, politicians, parents and information about the rights of people with disabilities.

On the basis of the similarities of the two National Disability Strategies, it can be surmised that the first programme did not succeed in resolving many of the issues prioritised in the Strategy.

Consequently, the Ministry of Social Welfare (now the Ministry of Health and Care Services) took the initiative in discussing with other relevant Ministries, aspects of the Strategy which could be implemented in the ordinary work/responsibility/budget of each Ministry, in other words it wanted to mainstream the Strategy.

The contribution of NGOs was relatively strong and this was emphasised by the Government. It is interesting to note how similar both of their priorities were.

The first two National Disability Strategies operated through a series of projects. Of the 381 projects, NGOs were responsible for 108 of them, the Ministries for 122, and the rest were operated by local authorities, professionals, etc.

Projects were classified in terms of whether they included user participation or if they were user controlled, and a total of 95 projects had full user control. User participation ranged from 36% in research into living conditions to 88% in user participation projects.

The focus of the projects included:

Competence centres for groups with rare disabilities	98 projects
IT for the disabled	27 projects
User Participation – training etc.	26 projects
Care services, young disabled, developing personal assistance	19 Projects
Information programmes	17 Projects
Living conditions - research	14 Projects
Sign language for different target groups	10 Projects
Equality of status for disabled women	6 Projects

The different measures in the two National Disability Strategies were distributed amongst the Ministries responsible based on the type of services involved, so for nine of the programmes, between two and three Ministries had a shared responsibility.

The second National Disability Strategy had a total of 90 concrete measures, some of which had started during the first Strategy. The specific responsibilities allocated to each Ministry are presented below. Note that the titles of the Ministries are their current titles.

Ministries	Responsibility (90-93)	Responsibility (94-97)
Ministry of Health and Care Services	18	36
Ministry of Labour and Social Inclusion	12	8
Ministry of Education and Research	5	11
Ministry of Foreign Affairs	5	3
Ministry of Culture and Church Affairs	4	10
Ministry of Transport and Communication	4	10
Ministry of Trade and Industry	3	5
Ministry of Children and Equality	0	8
Ministry of Government Administration and Reform	2	1

The National Disability Strategies prioritised projects that would make society better adjusted to the needs of people with disabilities and stressed the principle that mainstream service providers have a full responsibility for the needs of citizens with disabilities. In consequence, the Strategies provided these organisations with the capability of establishing specialised programmes and arrangements.

The main principle underpinning the National Disability Strategies was that people with disabilities should experience living conditions which are the same as those citizens without disabilities, in terms of living, working and housing in mainstream society.

A description of the Strategies

The first National Disability Strategy was a concrete result of the NOU (1983:36, "Strategy Plan for the 1980s"). The main focus of this Strategy was to create activities in areas which had been, more or less, neglected up until then. The different Ministries were instructed to implement fifty new, concrete measures/ reforms during the period of the Strategy, and a total of ninety measures/ reforms were included in the second Strategy.

Financing:

The 381 projects were categorised in terms of content and scope, and funding was allocated accordingly:

- 66 projects were awarded more than €125,000;
- 64 projects were awarded between €62,000 and €125,000;
- 125 projects were awarded between €12,500 and €62,000;
- 103 projects were awarded between €1,254 and €12,500;
- 23 projects were awarded less than €1,254.

This shows the wide variation in the scale of the projects. No project was particularly large, however, some projects received significantly more resources as they were co-financed with the budgets from other Ministries.

Research:

In both the first and second National Disability Strategies, different research was carried out in the field in order to determine the best way to organise measures and reforms and to identify innovative approaches. Such research aimed, for example:

- To find suitable models to build cross-disciplinary professional competence concerning rare disabilities/diagnosis. These disabilities are so rare that it is not possible for local authorities to built up their own competence. Four different centres were established and for some groups of disabilities a Nordic professional cooperation was established because they were so rare.
- To test the suitability of IT-technology/hardware for different groups of disabilities.

Results:

As a result of the scope and scale of the projects funded during the Strategies, a wide range of topics was covered. Initiatives ranged from the production of small information flyers to the establishment of substantial centres of expertise. Some of the projects were aimed at providing better explanations of the processes underlying particular impairments and were expected to produce reports with suggestions for reforms. Consequently, it is not easy to describe the concrete results for all of the projects. Nevertheless, only twelve of the total of 381 projects did not succeed as intended, giving a failure rate of only 3%.

Final reports were produced for all of the projects, and 38 of the more substantial ones had an external evaluation. Finding competent evaluators/researchers was often a problem, and an interesting side effect of the National Disability Strategies was a build-up of these competences in Norway.

All the partners involved in these two National Disability Strategies stressed the importance of extensive and varied access to information. Some of the issues raised by the partners are described below.

- The NGOs put a lot of effort into trying to change attitudes with regard to a “non-discriminating society”. Information was sent to 13,000 local politicians and 7,000 local administration leaders under the slogan “new knowledge – new action”. The evaluation showed that 25% of local communities increased their effort in this field, but also that only 42% had their own plans for people with disabilities. The major gaps in services were identified as being community-based psychiatric care, suitable employment, accessible information, culture/leisure services, and medical rehabilitation. A positive result of the first Strategy was that many communities established a local Council for people with disabilities during the period.
- Information about the role of Support Persons and a campaign to recruit more participants for this service was based on strong demand from NGOs. An evaluation indicated that 62% of local communities had received this information package and it was considered very useful for awareness-raising. About 3,000 Support Persons underwent training, which was subsequently included as a course in the mainstream education system. More Support Persons were recruited by a total of 23% of the local communities, and as such, the number of Support Persons increased from 5,000 to about 7,000 over the duration of the two Strategies. By the end of the first Strategy, this service had become part of social services legislation. In the second National Disability Strategy, the information strategy also included the concept of leisure time assistance and the Support Persons campaign was directed more towards people with a psychiatric disability.
- In the second National Disability Strategy, one important focus was “availability of food”. The focus was about providing better access to food for people who have special dietary needs for different reasons. This was organised in a three year project in cooperation with different public authorities and relevant NGOs.
- The Equal-Work service initiative was also strongly supported by NGOs. This service consists of different streams, such as organising self-support groups, a visiting service, telephone-contact and exchanging of information. In the first National Disability Strategy, a financing system for NGOs was developed for this type of work, and in 1996, a total of 66 NGOs received support in this way. The system has since been evaluated and has been the subject of extended debate about how to define the terms of an Equal-Work service. The type of service delivered was very dependent on the type of NGO running the service. This evaluation was followed up by a user study in 1993 – 1994 involving 44 NGOs. It concluded that the service produced the best results in smaller organisations, where

condition-related sense of camaraderie was stronger rather than in larger NGOs which cater for more common conditions. As a result of these evaluations, financial support for this type of service has been mainstreamed into the support structures of the statutory authorities since 1998.

Mainstreaming (sector responsibility) policy

In the late 1990s, almost sixty measures were transferred into mainstream responsibilities of various Government Departments:

- 20 were integrated into services under the Ministry of Health and Care
- 14 became services under the Ministry of Labour and Social inclusion
- 8 services were adopted by the Ministry of Education and Research
- 7 services were brought under the responsibility of the Ministry of Culture and Church Affairs

Did the first two National Disability Strategies make an important change?

The final report from the first National Disability Strategy (1990 – 1993) concluded that Government Ministries had been strongly involved in a range of measures, and that many of the measures would, most probably, never have been realised without the Strategy.

The same conclusion was reached in relation to the second National Disability Strategy (1994 – 1997). But is this sufficient to conclude that the first two National Disability Strategies changed disability policy in Norway? It is difficult to reach any conclusions because the measures involved and the budgets allocated for the Strategies represent a very small part of the total budget related to all measures for people with disabilities.

The conclusion of the Ministry of Health and Care was that the process in itself, in terms of working out plans for measures and projects, was important, because it increased consciousness of the need for a better policy approach to disability amongst a wide range of actors in the disability field in Norway and, in particular, heightened awareness of the importance of user participation.

Nevertheless, the Government adopted a totally new strategy in the third National Disability Strategy (1998 – 2002).

The third National Disability Strategy 1998 – 2002 (now called Plan of Action)

In the mid to late 1990s, the Norwegian Storting (Parliament) discussed a White Paper (St. Meld. No 34 (1996 – 1997), which summarised the status of people with disabilities as a result of the first two National Disability Strategies. In response to this, there was widespread political agreement about the key challenges to improving the life circumstances of Norwegian citizens with disabilities.

A second White Paper, proposing a new Plan of Action for People with Disabilities (1998 – 2001), later extended to 2002, was the direct result of (St. Meld No. 8 (1998 -1999). This White Paper dealt with objectives and strategies for the future and focused primarily on measures to improve physical accessibility in society, and contained an extensive 'Plan of Action'.

The plan of action had four areas of commitment:

- An accessible society
- Planning and user participation
- The rights of persons with disabilities
- Ensuring that persons with disabilities are in employment

The mainstreaming (sector responsibility) principle formed the basis for the follow-up of the Plan of Action, and the Ministry of Social Affairs coordinated this work through the Committee of State Secretaries, which was responsible for the overall policy with regard to people with disabilities. Consequently, most of the measures in this plan were financed through prioritisations in the ordinary sector budgets, and the status of the follow-up of the Plan of Action was reported annually in the form of a separate report.

In order to monitor the Plan of Action, the Government appointed a Commission in April 1999, to assess various strategies and tools for promoting the objectives of full participation and equality for people with disabilities. The Commission presented its recommendations in June 2001 (NOU 2001:22 – From User to Citizen).

The Commission had carried out a broad review of the structural and institutional frameworks relating to people with disabilities and identified a range of disabling barriers in various areas. In most areas, a gap existed between political objectives and the reality of conditions experienced by people with disabilities in Norway.

The Commission concluded that, despite improvements in several areas, the objectives of implementing the basic principles of equality, mainstreaming (sector responsibility), compensation, user participation and universal design had not been sufficiently successful. The fundamental conclusion of the Commission was there was a long way to go before the objective of full participation and equality could be reached.

As such, the Commission proposed the following measures:

- The introduction of an anti-discrimination law for people with disabilities to prohibit discrimination and promote equality,
- The strengthening of existing legislation in order to ensure that people with functional impairments are treated equally,
- The creation of a Board to oversee the rights of people with disabilities. Among other things, this Board should be responsible for monitoring and documenting discrimination and for contributing to greater access to legal assistance for persons who are subject to discrimination,
- More substantial disability research in order to document and reveal deviations between objectives and the reality of the life circumstances of people with disabilities and to strengthen the impact of disability research, amongst other things,
- The creation of a documentation centre to gather and disseminate knowledge and maintain an overview of research and development work in the disability field,
- The operating subsidy given to organisations representing people with disabilities for their lobbying work was increased considerably,
- The creation of mandatory meetings between representatives of organisations for people with disabilities, and politicians/public administration employees in all of Norway's municipalities.

The committee was divided in its views about whether the municipalities should be ordered by law to establish municipal boards for people with disabilities. The committee proposed making user participation a statutory obligation, but did not support the idea that municipalities should be required to prepare municipal plans of action for people with disabilities.

In the second part of the strategy, the commission proposed three prioritised areas of commitment:

- Full access to transport for everyone, meaning that public transport and its associated infrastructure (means of transport and terminals) are to be accessible by 2012.

- Full access to buildings and structures for everyone. The premises of publicly elected bodies are to be accessible by 2005; to other public buildings by 2006; to kindergartens, schools and universities by 2007 and to work premises and buildings by 2008.
- Full access to information and full access to ICT by 2005.

The report of the Commission was subject to the normal round of consultations and, as a result, the Ministry of Health and Care services received around 140 position papers. This was the main resource incorporated in the next White Paper (nr. 40, 2002–2003 – Dismantling of Disabling Barriers).

The next step occurred in November 2002, with the government appointing a legislative committee to investigate the need for legislative and judicial measures to strengthen the legal status and protection against discrimination of people with disabilities. This report (NOU 2005:8 – Equality and Accessibility) proposed that :

- The conclusions of the Committee should be incorporated into a separate Act against discrimination on the basis of disability.
- The Committee recommendation that the Government as soon as possible should appoint a separate legislative committee to consider the desirability of a single joint Act against discrimination in Norway and that, if appropriate, such an Act should be drafted.

Commentary and Conclusions

There is evidence, in the process of the three consecutive National Disability Strategies, that an initial acceptance of disability as a significant social policy issue can, over time, lead to substantial changes in the way the State and other citizens regard disability. Distinctive changes in Norwegian disability policy can be seen from the first to the third Strategy.

There was relatively minimal cooperation in the 1980s, when some structures were established that would further lay the ground for the three National Disability Strategies, which operated from 1990–2002. A key driver of change was the United Nations Decade of People with a Disability, which declared full participation and equality of status as its main objectives, and this placed extra pressure on Norwegian policy to reform. The UN Standard Rules in 1993 inspired debate even further, and more recently, the NOU 2005:8 – Equality and Accessibility paper is directly related to the process which has led to the new UN Convention on the Rights of People with Disabilities, which Norway has ratified.

Looking towards future developments, it was reported in the *Dagsavisen* newspaper, on 6 June 2007, that the Director of the Directorate of Social and Health Services had announced that the Norwegian Government would, in autumn 2007, propose a new Act concerning discrimination and accessibility. This can be seen as the natural result of a long process towards improving the living situation for people with disabilities in Norway.

With regards to the first two National Disability Strategies, they were similar in the fact that they both had separate budgets and the main measures/reforms were concerned with information and improving the situation for groups of people with rarely diagnosed disabilities. They also built a strong NGO sector which has since served as a valuable resource in Norway's approach to disability. The third Strategy, the Action Plan from 1998 – 2002, stressed the principle of the mainstreaming (sector responsibility) principle. Although this was a big shift, it can actually be seen as a logical development after the progress made by the first two Strategies.

There may well be no further National Disability Strategies in Norway, since the forthcoming Act on discrimination and accessibility is regarded as being sufficient to resolve the remaining difficulties and barriers experienced by people with disabilities. The aims of this Act will only come to fruition, though, if the principles of mainstreaming and sector responsibility lead to a process of continuous improvement for people with disabilities. It is currently too early, however, to surmise whether the initiatives put in place over the past fifteen years in Norway are sufficiently robust to deliver on this aspiration.

While Norway allocates a very substantial budget to activities relating to people with disabilities, there will always be demands for more resources in fields such as housing, pensions, suitable work and social participation. Nevertheless, it is legitimate to conclude that over the past 15-20 years, the specific focus on disability, through the three National Disability Strategies, has created a process within which continuous improvement for people with disabilities is possible.

IV.3 Ireland

Introduction

The origins of the Irish National Disability Strategy can be found in the broader international Independent Living Movement and, in particular, in the dissemination of values by Disabled Persons International (DPI) during the 1980s, which were put in place for the UN Decade for People with Disabilities. As a result, the key drivers for change, within the Irish context, were the creation of a coherent disability movement in 1989 and the formation of a strong partnership with the Irish Labour Party. As a result, the founding principles of the Irish Strategy are:

1. Equality – in terms of a formal equal opportunities and non-discrimination response in legislation, a focus on equality of outcomes and opportunity rather than on equal treatment, the principle of equality of representation of people with disabilities in all consultative and planning activities, and affirmative action and positive discrimination in favour of people with disabilities, in order to redress past inequities.
2. Participation – in terms of user participation in the planning, development, and implementation of services and the formulation of policy.
3. Independence – in terms of personal assistance to cope with the demands of everyday life, and control, in terms of making quality of life decisions.
4. Choice of quality services – in terms of the requirement for service standards and the provision of genuine choice in community services, facilitated by direct funding to users rather than organisations.

Prior to the change of structures and approaches, Irish legislation only acknowledged disability in two sections of two Health Acts. As a result, the Department of Health responded to all aspects of disability, which led to a general acceptance that the medical model was the pervasive model. Even labour market participation was dealt with by the Department of Health. In addition, there was always a very strong voluntary/not-for-profit sector in the provision of services, and it is widely acknowledged that without the contribution of the voluntary sector and often religious organisations, the Irish education system could not have developed in the way it has.

In 1965, the government brought into place a regulation to set up a coordinating body for rehabilitation services. The National Rehabilitation Board had the remit to coordinate all non-governmental services, but was not in a position to coordinate statutory provision, which was operated and financed by the regional health boards. As a result, the evolution of disability services owed more to the energy and commitment of local groups than to the systematic implementation of a national strategy.

In 1975, substantial resources began to flow into the Irish economy from the European Economic Community. The European Social Fund provided unprecedented resources for both capital and current expenditure. The positive impact of European funding on Ireland as a nation is unquestionable, and there is little doubt that people with disabilities also benefited significantly from vocational training, funded by the European Social Fund.

However, there were two less than positive side effects of European Funding. Firstly, because European financing required matching funding, ESF tended to divert resources into vocational training from other types of services, such as day-care, respite care and home assistance.

Secondly, the model of service proliferated with the assistance of the ESF was based on the concept of community workshops in which people with disabilities were introduced to either low level industrial activities or manual trades. It was not until the early 1980s that vocational training at the technician's level was introduced for people with disabilities. Throughout this time, the state training agency provided training to people with disabilities but the numbers involved were relatively small.

Given this context, it is not surprising that the report of the Commission on the Status of People with Disabilities (1996) 'A Strategy for Equality', described people with disabilities' views of the Irish system as being very negative. It reported that people with disabilities in Ireland felt marginalized, access to infrastructure and information was very limited, services were either non-existent or fragmented and the Irish government had never collected any statistical information about people with disabilities since the foundation of the state.

The report of the Commission was the most obvious catalyst for change in Ireland. However, it is important to recognise that the commission itself resulted from a collaboration between the Forum for People with Disabilities (A Representative Organisation of People with Disabilities) and Government.

It was through the relationship between the Forum and the Labour Party that the concept of the Commission was incorporated into the Labour Party's programme for government. In turn, it was through the Labour Party that the Department of Equality and Law Reform was established. It was the Minister for Equality and Law Reform who took the decision to establish the Commission in 1993.

The Change Process

The membership of the Commission was made up of 60% representation of people with disabilities or their families, and 40% was made up of service providers and other stakeholders. The Department of Equality and Law Reform took the leading role by providing substantial administrative and expert resources to the Commission in the implementation of its work. The main umbrella bodies representing the not-for-profit sector were also represented, and the National Rehabilitation Board provided substantial logistical support to the process.

The Commission carried out extensive consultations throughout Ireland. It received over 120 written submissions from organisations and from individuals with disabilities. In addition, it opened 'listening meetings' in a wide range of local areas throughout Ireland. A listening meeting entailed advertising a public meeting in the local press that was held in the evening, so that working families could attend, and inviting people in a public forum to express their views about the way in which people with disabilities were treated in Ireland.

As it transpired, the implementation of the Commission process was fortuitous in that in 1993, the UN published the Standard Rules for the Equalisation of Opportunities for People with Disabilities. As a result, the Commission had the ideal blueprint for structuring its findings and recommendations. It is no coincidence that the chapter structure of the Commission's report strongly reflects the articles of the UN Standard Rules. However, the Commission's report differed in two significant aspects from the UN standard rules, in that rehabilitation and medical intervention were both omitted from the Commission's report. The extent to which the blueprint proposed by the Commission reflects the UN standard rules is evidenced by the fact that Ireland was given the Franklin D. Roosevelt Award for Best Practice in Disability in 1998, two years after the publication of the report.

Representative organisations of people with disabilities played a key role in the change process in Ireland. It was the Forum for People with Disabilities and the Centre for Independent Living (CIL) that were the motivators and formulators of the initial concept of the Commission. They fostered strong relationships with both Government and politicians and continued to work with them right through the Commission process. During the implementation process, disagreements and a fragmentation of consensus occurred, but at key moments the disability sector has managed to act with one voice to influence policy and legislation during the implementation phase.

A number of the individual contributors to the disability debate in Ireland were members of the Trade Union movement. At a certain point in the process, the Irish Congress of Trade Unions provided crucial support to the disability movement in its campaign to promote a rights-based approach to disability in Ireland. The Irish Congress of Trade Unions participated fully in the Commission process, and through the European Social Fund it implemented a number of pilot projects, which were useful in the rolling out of the Commission's recommendations in practical terms. The Irish Business and Enterprise Council (IBEC) also participated in the process, and while initially acting as positive observers have, over a number of years, taken a very active role in relation to promoting disability within the workplace. The activities of IBEC have been supported by the Equal Programme.

At the early stages of the Disability Movement's campaign for equality and choice, the main targets for criticism were service providers. In retrospect, it is undeniable that there were grounds for these criticisms. Issues of institutionalisation and disempowerment could be identified throughout the service provision system, and there was major concern about the impact of segregated special education and vocational training of people with disabilities. The recommendation in relation to this by the Commission was to implement a process of mainstreaming.

As a result, responsibility for vocational training for people with disabilities was removed from the Department of Health and re-allocated to the Department of Enterprise, Trade and Employment, and specifically to the state training agency, FAS. This was, both at a policy and administrative level, a mainstreaming action, and resulted in many service providers withdrawing from the provision of vocational training. All in all, service providers have cooperated with and contributed to the change process, although it is difficult to assess the extent to which this has resulted in the slowing down of changes in certain areas.

The main preparatory initiative for the change process in Ireland was the Commission process. The Commission's report made 404 recommendations, and a recent estimate of the number of recommendations acted upon was extremely positive, with at least some progress having been made on 80% of the recommendations. However, the most striking impact was the way in which the process itself raised awareness amongst people with disabilities about the inequalities they were facing and the negative implications of the application of the medical model to policy and the planning of services.

The impact of the Commission process resonated beyond Ireland's national boundaries when in 1996, during the Amsterdam process, the Commission drew the attention of the Irish government to the need for a Member State to promote the non-discrimination clause in the European Treaty and, as a result, Ireland, who held the presidency at the time, sponsored Article 13 of the Amsterdam Treaty.

The Irish National Strategy

After the publication of the Commission's report, there was a two-year hiatus, as a result of a change of Government and a review of priorities. The Department of Equality and Law Reform was merged with the Department of Justice to create a new governmental portfolio, which has had responsibility for the implementation of the Irish National Disability Strategy over the past ten years. From 1998 to 2006, an energetic legislative programme has been followed by the Irish government with a view to completely restructuring the Irish response to disability.

The first piece of legislation to adopt this new approach was the Education Act (1998), which introduced a responsibility upon the educational system to respond to the needs of individuals with disabilities and also established the first definition of disability in Irish law. This was quickly followed by an Employment Equality Act (1998), which outlawed discrimination against people with disabilities in the vocational training, recruitment and career development processes. The Employment Equality Act was a general non-discrimination measure which specified nine grounds upon which discrimination is illegal.

This was followed by the Equal Status Act (1999), which extended the non-discrimination requirement to providers of services, including educational services. Two other key acts were passed that year to establish what have become known as the new structures. The National Disability Authority Act (1999) set up an agency with responsibility for overseeing the implementation of the new law, collecting statistical information about the status of people with disabilities in Ireland and promoting and encouraging standards in services.

The other agency that was established was 'Comhairle' (Comhairle Act 1999), formed from the personal advisor service of the National Rehabilitation Board, which was disestablished at this time, and the National Social Services Board (NSSB), which operated citizen's advice bureaus. The intention was to mainstream information, advice and advocacy services for people with disabilities.

The mainstreaming process entailed the disestablishment of the NRB, the removal of responsibility for vocational training from the Health Boards, and the re-allocation of this to the National Training Agency, FAS. Staff from the NRB were re-allocated to roles within the new structures or within FAS, and in June 2000, at a large conference held in University College Dublin involving all stakeholders, the new structures were launched. The implications of the new structures upon the day-to-day lives of people with disabilities is difficult to evaluate, even five years after their launch, but it is generally recognised that the programme was incomplete and that a further set-up legislative initiatives were required.

In 2004, a second phase of legislative activity took place, which involved the Education of Persons with Special Education Needs Act (2004) becoming law, and the publication of the National Disability Strategy (2004). The Education Act 2004 provided students in primary and second level education with the right to an individual educational plan. All services and interventions specified within the IEP have a mandatory basis in law in that the Minister for Education must, if not in the current year then in the subsequent year, find the resources to meet the resource requirement specified in the plan. In order to operate this system, a National Council for Special Education was established to act independently from the Department of Education to co-ordinate and implement the individual planning process.

The National Disability Strategy (NDS) also involved legislation, namely the Disability Act 2005, which replaced a Bill originally introduced in 2002 but which was rejected by all key stakeholders in the disability sector and as a result was withdrawn by the Government. The NDS also includes a Bill to amend the responsibilities of Comhairle to empower it to act as an advocate for people with disabilities who are vulnerable.

Another key element of the National Disability Strategy was the proposal that a number of Government departments would be required to produce sectoral plans, describing not only how they intend to act over the next five years to enhance the life choices of people with disabilities, but also how they will co-operate with other Government departments in cross-sectoral activities. In any event, the Disability Act was passed in 2005 and the subsequent sectoral plans were published in 2006.

It has taken ten years for the change process in relation to disability to result in a fully specified NDS. While it is still too early to evaluate the impact that the strategy will have upon people with disabilities in Ireland, it is possible to say that the Irish approach to creating a NDS is unique in that its implementation is based on first principles and that it clearly attempts to achieve a cross-sectoral response to disability.

The Irish National Disability Strategy has at its core, the concepts of equality and mainstreaming, and it makes use of a wide range of different mechanisms to put these principles into operation.

- Both the National Action Plan for Employment and the National Action Plan for Social Inclusion have incorporated a range of specific initiatives aimed at promoting greater participation of people with disabilities within the labour market and within wider society.
- The Disability Act 2005 expanded the concept of individual planning originally formulated within the Education Act 2004 to set out procedures through which people with disabilities not in primary or secondary education can access an individual assessment of need (IAN). This needs assessment process has been placed with the remit of the Department of Health and Children and specifically refers to health and social care needs. It additionally specifies the important relationship between the IEP which is the responsibility of the Department of Education and which can specify health needs and the IAN, which has responsibility for also documenting the educational needs of adults with disabilities.
- The Disability Act 2005 also created the framework for the establishment of a Centre for Excellence in Universal Design and specified targets for creating accessible transport and physical infrastructure, particularly within public buildings.
- A further mechanism established by the Disability Act 2005 was the creation of a legal requirement upon the civil service and public sector organisations to meet a 3% quota of employees with disabilities.

- Finally, the Act restricted the use of information from genetic testing for employment, mortgage and insurance purposes.
- With the publication of the sectoral plans in 2006, the final plank in the National Disability Strategy's platform was put in place. The sectoral plans apply to the Department of the Environment and Local Government, the Department of Enterprise Trade and Employment, the Department of Social and Family Affairs, the Department of Health and Children, the Department of the Community, Marine and National Resources and the Department of Transport. This represents a broad sweep of mainstreaming measures. No sectoral plan was published by the Department of Education on the basis that the Education Acts 1998 and 2004 clearly specified the responsibilities in their sector.

In addition to the departmental responsibilities at Governmental level, the statutory agencies operating under these departments not only have to meet the 3% quota in terms of employing people with disabilities, but they also have specific responsibilities in implementing the National Disability Strategy. In this regard:

- Local authorities have responsibilities in relation to creating accessible physical environments at community level and providing support and financial assistance in adapting housing.
- In the employment sector, the National Training Agency, FAS, has responsibility for providing not only vocational training and recruitment assistance but also supported employment services and the provision of grants and subsidies to adapt the workplace. FAS also have responsibility for administering a re-integration grant for people who acquired disabilities while in employment.
- Comhairle, the information and advice agency, has an expanded remit and thus has responsibility for providing information, advice and advocacy to people with disabilities and particularly assisting those who are most vulnerable in acquiring the services and supports for which they are eligible within the system.
- The Health Services Executive has responsibility for carrying out the individual assessments of need and for coordinating the delivery of services and interventions identified by the assessment. The Department of Health and Children has also set up a Mental Health Commission to examine the mental health sector with a view to re-engineering the provision of mental health services based on a model of recovery and equality.
- Under education, the National Council for Special Education has responsibility for operating the individual education programming process and for providing support to schools through a network of special educational needs organisers.

- Under the Department of Equality and Law Reform, the National Disability Authority has responsibility for monitoring the public sector quota, establishing the Centre for Universal Design, monitoring the National Disability Strategy, reviewing progress on the sectoral plans and producing national data on the status of people with disabilities in Ireland.
- The Equality Authority has responsibility for monitoring the implementation of the Employment Equality Act and the Equal Status Act. Cooperation between the NDA and the Equality Authority has resulted in a number of key studies documenting the current response to disability in Ireland.

While the responsibilities of the statutory sector are well specified and described within the legislation and the sectoral plans, the role of the non-governmental sector including not-for-profit and private sector providers is less well documented. Nevertheless, there is general acceptance that the state cannot deliver on the commitments under the NDS without a strong non-governmental sector. There are provisions within the strategy to introduce, on a phased basis, national standards for all services for people with disabilities. In addition to the service providing community, area partnerships that were set up to coordinate actions at a local level have also incorporated within their remit a response to disability issues at community level.

The social partners have also been very active in developing and implementing strategies to increase participation within the labour market for people with disabilities.

One initiative, which was implemented by the Department of Health and Children prior to the publication of the National Disability Strategy, needs to be highlighted. In cooperation with the Health Research Board, the Department of Health and Children established a National Services Database for people with intellectual disabilities. This database is designed to document the service needs of the target group on an individual basis in terms of current needs and possibly future needs within the next five years. The National Intellectual Disabilities Database has 93% coverage and is a very useful tool to generate service planning information which can be utilised by multi-disciplinary public/private planning committees at regional level.

More recently, a National Physical and Sensory Disabilities Database was established. While national coverage in this database has yet to reach 80%, the information generated by the database has been extremely useful in identifying areas where service development needs to occur. The National Physical and Sensory Database also includes a measure of activity and participation based on the ICF, which has the potential to provide ongoing feedback to service funders and service providers about the extent to which people with disabilities in a local area are participating in society and the barriers which they face.

Commentary and Conclusions

The establishment of the Irish NDS has been a long and arduous process and one that has not always evolved without deviation or difficulty. Despite the challenges faced, it is fair to say that a relatively coherent set of processes and structures have been put in place to deliver on a coherent policy platform.

While it is difficult to assess the extent to which the measures introduced in the National Disability Strategy will impact in the medium to long term, it is possible to review the effectiveness and impact of the structural changes that occurred in June 2000. One of the major challenges facing the system, as a result of restructuring, is achieving coherent and coordinated service delivery for people with disabilities.

Particular difficulties arose with the disestablishment of the National Rehabilitation Board. The NRB had over the years established itself as a well-known entity within the community. While there were some issues in relation to the NRB, concerning long waiting lists for assessment and the narrowness of its remit, it had over the years, established a relatively well-structured system of information, advice and coordination. The personal advisors of the NRB carried a caseload of people with disabilities and followed people up to determine the success of interventions and their current status.

In the absence of the NRB, this key function disappeared, and as a result, the mainstreaming of disability responsibilities left a gap within the system. In the original proposal of the Commission on the Status of People with Disabilities, it was intended that there would be a Disability Support Service (DSS), which would act as a one-stop-shop for people with disabilities in relation to information, advice and advocacy. In the event, the DSS was mainstreamed into the National Social Services Board.

In the early stages, the new organisation Comhairle interpreted its remit as purely the provision of services within the remit of the Department of Social and Family Affairs. As a result, Comhairle was not particularly active in other areas such as health, employment and education. The resulting gap in information and advice services made it difficult for people with disabilities and their families to identify appropriate services and supports. It is to be hoped that the Education Act 2004, the Disability Act 2005 and the Comhairle Amendment Bill will redress this issue and ensure that people with disabilities have easy access to information and advice.

A second challenge has been mainstreaming. While this has occurred at the policy level, progress on the ground has been relatively slow. Part of the problem in this regard was the lack of understanding on the part of mainstream agencies of the concept of 'mainstreaming.' The initial perception of mainstream agencies was that they would not have to change the way they operated because people with disabilities were being mainstreamed and thus would have to cope with the way in which things were being operated currently.

In fact, it became clear very quickly that the structures being operated by the mainstream agencies could not cope with the needs of people with disabilities and the range of individual differences involved. Of particular concern was the way in which these agencies responded to people with mental health difficulties. Over the last five years there has been a major re-think on the part of the mainstream agencies and staff training

and development in relation to disability issues has been prioritised and more responsive structures are being put in place.

In addition, the providers of special education and specialised vocational training have been operating relatively effectively over a period of fifty years. It is difficult to disestablish such structures, particularly when they are providing high quality services to people with difficulties. There is clearly a need to review the relationship between the specialist providers and mainstream providers in this regard.

Another challenge that is emerging is the lack of emphasis upon direct funding or personal budgets. When one reviews disability strategies in other jurisdictions, the provision of opportunities to control their own funding for people with disabilities has been one of the central elements of the strategy. In Ireland, the concept of personal budgets and micro-boards has been experimented with on a pilot basis, but no specific mechanism has been put in place within the NDS to enable this approach to be adopted easily.

There is little doubt that a basic challenge facing the Irish government in the implementation of the NDS is one of accelerated demands for resources. At the present time it is possible to perceive within the actions of a number of state bodies, the adoption of conservative approaches aimed at limiting the resource impact of the new legislation. This has the effect of limiting the intended impact of the measures. The Disability Act had attempted to redress this problem by introducing the concept of multi-annual funding. Prior to this, government expenditure was allocated to the disability sector on an annual basis. As a result, any unused resources would disappear at the end of the year and important initiatives and programmes had to be re-budgeted for the following year. Multi-annual funding means that certain elements of the NDS can rely on a longer term budgeting framework which will allow the movement of resources from one year to the next in order to achieve strategic goals.

Another challenge for the system arises from the fact that although legislation empowers a range of actions on the part of the Government, a number of key elements of the strategy have not been 'commenced', which means that the relevant minister has not signed them into law. An example of this is the entitlement to an individual educational plan for people with disabilities in primary and secondary education. While it is three years since the Education Act 2004 was passed, many of the elements associated with individual educational planning have not yet been signed into law.

In conclusion, the evolution of the Irish NDS from its inception in 1993 with the establishment of the Commission on the Status of People with Disabilities to the publication of the sectoral plans in 1996 was a long and arduous journey. Along the way, certain aspects of the strategy were dropped and others changed substantially. Thus, while it is possible to recognise the current state of affairs within the original recommendations of the Commission, it is safe to say that the current system is not purely based upon the blueprint provided.

The main conclusion to be drawn from the Irish experience is that it is possible to start from first principles and re-design in a fundamental way the way in which a nation responds to its citizens with disabilities. It is also possible to identify the importance of the participation of organisations of people with disabilities in the policy planning, design and implementation process. Another important lesson that can be learnt is that it is possible

to create cross-sectoral working between various Government departments, but it is essential that there is a designated agency with responsibility for ensuring that coordination actually happens and that it impacts upon services on the ground.

The use of Individual Assessments of Need and individual plans to coordinate services for people with disabilities has the potential to eliminate the information gap that currently exists at the centre of the Irish system. Further, the broadening of Comhairle's remit to include advocacy is welcomed. However, it is interesting to note that the Disability Act 2005 has two different definitions of disability. One definition which applies to the majority of the Act has a broad remit and has the potential to include within its remit the majority of people experiencing a reduction in functioning. However, part two of the Act, which specifies eligibility for an Individual Assessment of Need, uses a much more restricted definition of disability and as a result it is estimated that perhaps 50% of people experiencing reduced functioning will not qualify for an Individual Assessment of Need.

There are many lessons that can be learnt from the Irish approach in relation to the process of establishing a NDS, and perhaps the most important of these is that there is not need to 're-invent the wheel.' Specifically, Irish organisations of people with disabilities, service providers and the State have derived much of the strategy not only from practice in other jurisdictions but also by utilising the international instruments available in relation to disability policy. In 1993, the UN standard rules provided an adequate framework for the formulation of the Irish disability policy platform. Currently, the UN Convention on the Rights of People with Disabilities and the Council of Europe Action Plan provide a more coherent and well specified framework.

V. Key Issues and Challenges in Policy Implementation

The key challenges that policymakers face in the field of disability arise not so much from the development and passing into law of principles and policies. They stem, however, from the design and operationalisation of the mechanisms for implementing these principles and policies and from the mediating structures which translate them into meaning in the day to day lives of citizens experiencing reduced functioning as a result of developmental, acquired impairments or chronic disease.

There is widespread recognition across cultures and jurisdictional boundaries that current systems and structures to respond to disability are less than optimal. In developed economies, there is evidence of increasing numbers of people being registered as economically inactive and in receipt of pensions as a result of disability. The relationship between disability and age is becoming ever more apparent and the number of people exiting the labour market through early retirement as a result of health related difficulties is increasing.

In parallel with these developments, a number of important values, principles and strategies are being proposed, some of which have become adopted on a wide scale, despite lack of evidence for their impact on the day to day lives of citizens with disabilities. This section provides a brief and selective overview of a number of such policies and strategies. Each is described with reference to the experience of other jurisdictions which have attempted to implement them.

V.1 Disability Rights Legislation

The first civil rights legislation to specifically target people with disabilities was passed in the United States in 1992 (American's with Disabilities Act). At the time, it was accepted that a rights-based approach to disability would largely resolve many of the issues of exclusion and discrimination being experienced by the majority of people with disabilities. Since that time, the pervasiveness of equal rights and non-discrimination legislation has increased with the adoption of Article 13 of the Amsterdam Treaty and the passing into law of the Non-Discrimination Legislation in a wide range of EU Member States.

In support of the non-discrimination agenda, the EU Directive on Equal Opportunities has provided a framework for national initiatives and legislation. At this stage, most developed western economies have some form of non-discrimination measure in place. The promotion and protection of the rights of people with disabilities has now become an accepted policy approach at international level with the passing of the UN Convention to protect the rights of people with disabilities.

However, it is useful to contrast the diverse nature of the UN Convention with the narrow focus of many equal rights measures at national level. While there is no argument that a rights-based approach is an essential ingredient in an effective disability strategy, it is no longer clear that passing equal rights legislation in isolation has the impact on society needed to reduce exclusion and promote more active participation.

In fact, in the two years subsequent to the passing of the ADA Act the number of people with disabilities in employment actually fell. This was due to the fact that employers were required to judge job applicants on an equal basis with non-disabled applicants. In the event, disabled job applicants had less employment experience than non-disabled job applicants and as such the issue of discrimination did not arise. It may well be that this was an aberration or a system adjustment as the employment rate for people with disabilities did return to pre-ADA levels over time but what is of more concern is the fact that over fifteen years since the passing of the ADA, employment levels of people with disabilities have not significantly increased beyond pre-ADA levels.

This is not to suggest that non-discrimination legislation is irrelevant but simply to emphasise the fact that non-discrimination legislation on its own cannot resolve all difficulties faced by people with disabilities in gaining access to full participation in society. In fact, the UN Convention recognises this by including within the convention a number of elements relating to service provision and support.

V.2 Direct Payments

There is a strong international movement promoting and supporting the concept of diverting fees for service from organisations and allocating them directly to individual with disabilities or their families. This direct payments approach has been in operation in a number of jurisdictions and there is local evidence that those individuals who utilise this method of purchasing services are very satisfied with the outcomes.

For example, in the UK, once a person has had a social care assessment, he or she has the right to opt for a personal budget with which to purchase the required services, or to have the services provided by the local authority. Those who opt for a direct payment are provided with training in how to administer their own funds.

There is a mechanism through which people who do not have the capacity to make decisions can participate in the direct payment scheme. This mechanism involves the establishment of a micro-board nominated by the person themselves with assistance from an advocate to administer the personal budget on their behalf. While there is accumulating evidence of the satisfaction rates for people with disabilities, there is less evidence of a positive impact on services.

In the first place, having a personal budget can only provide a person with choice if there is actually more than one service available to them in their neighbourhood. Secondly, providing individuals with a personal budget does not necessarily mean that they will use that budget. An example of this arose in the United States with the Ticket to Work Scheme in which all social security recipients were provided with a \$5,000 voucher which they could trade in for Return to Work services and training. The take-up of the scheme was very sparse and the impact on the number of people leaving the social security system was negligible. Clearly, the effectiveness of a personal budget approach depends on the way in which it is set up and managed.

V.3 Individual Needs Assessment and Planning

It is generally acknowledged that the concept of providing a person with a comprehensive assessment of their needs and production of an individual plan is a useful mechanism for ensuring linked services. This approach has been adopted in the US educational system for many years and has been available to students with disabilities in the UK since 1983. More recently, Ireland has also adopted a statutory approach to individual planning and assessment of needs.

A number of system inhibitors exist that can dilute the effectiveness and impact of an individual needs assessment and planning process. The first of these is when the agency responsible for identifying needs is also responsible for providing services to meet those needs. It is inevitable that concerns about resources will result in either needs not being documented or in individuals being delayed or denied an assessment of need. This was certainly the case in the early days of statementing within the UK. Thus, it is important that conflicts of interest are avoided within the assessment, needs and planning system.

A second issue arises in relation to the way in which plans are implemented. It is not sufficient to provide a person or their family with a documented individual plan if there is no support available to assist them to access the services they need or if information is not available to allow them to make an informed decision about which services to use. In the third place, when individual plan has a statutory basis, it is often the case that the plans become an administrative procedure that does not actually reflect the needs of the individual and are carried out to fulfil a regulation and neatly filed until it is time for review.

V.4 Eligibility For Social Protection

Once of the main drivers to respond to disability in a more active way is the burden that is being placed upon public expenditure budgets by disability pensions. The dilemma for policymakers is to balance the need to increase the numbers of people with disabilities who are actively seeking work without jeopardising the quality of life who genuinely require social security support.

One approach to this is to make eligibility assessments more stringent. This has the impact of declassifying people who are currently eligible for pension payments and rejecting the applications of others. The wisdom of this approach has to be called into question. There is a view that the more difficult the State makes it for people to access the social protection system, the less likely those who successfully achieve a disability pension will be in relinquishing a benefit.

There is evidence of this from the Stress Impact Study from which it emerged that in some jurisdictions people in receipt of disability income payments were less disabled than in other jurisdictions. However, it was in these jurisdictions that the greatest chance of returning to work was documented. In the United States, there is a proposal to move the assessment function for people who have lost employment as a result of an illness or injury from the social security remit into the labour office. This redirection would mean that people could be provided with a short-term disability benefit and offered an assessment of residual capacity, which would highlight strengths, rather than an assessment for eligibility which highlights weaknesses.

V.5 Early Intervention

The evidence supporting the view that early intervention can minimise the impact of an impairment is unquestionable. The earlier one intervenes for a child who is born with a developmental disability, the better the outcomes are for that individual developmentally. The earlier one intervenes with an emerging disability in the workplace, the more likely a person is to retain their job or to return to another job.

The key challenge for administering early intervention systems is that, particularly in the case of those in employment, many of the people who require services do not fit into the eligibility criteria currently specified for disability services.

Thus, current systems which are based upon on eligibility criteria which require individuals to meet a certain level of disability prior to gaining access to much needed services can actually contribute to greater impairments in people who are not currently eligible. From this perspective, early intervention and rehabilitation should be viewed as a mainstream service and could probably be seen as a right of all citizens.

V.6 Outcome Related Funding

A number of strategies to achieve more cost effective and efficient services have been implemented across different jurisdictions over the past ten years. One which was particularly popular in the United Kingdom in the 1980s and 1990s was Outcome Related Funding. This approach usually consisted of providing service providers with a proportion of a fee for service when an individual entered the service and withholding the greater proportion of the fee until a positive outcome had been achieved. In the case where an individual did not achieve a positive outcome, the second proportion of the fee was not paid.

The logic behind this is that service providers will act to get service users into employment at a faster rate and to re-engineer their services to achieve better outcomes. While there is some evidence that an emphasis on outcomes is an important aspect of financing arrangements for services, there are also substantial risks associated with the approach. In the first place, Outcome Related Funding encourages greater selectivity on the part of the service provider about which clients they accept and this can result in some people, particularly with mental health difficulties, not being able to access much needed services.

In the second place, Outcome Related Funding means that service providers are effectively giving credit to the State. Many service providers are not in a position to carry the debt levels required in order to participate in an Outcome Related Funding regime. As a result, service providers often exit those services in which the requirement for outcome related funding is in place. Others are forced to declare bankruptcy.

On the other hand, a system which simply funds on the basis of numbers in a service tends to encourage a more sluggish throughput of people in the rehabilitation system and de-emphasises results. What is required is a balanced system in which targets are part of service level agreements and sanctions for non-fulfilment of targets are in place.

V.7 Case Management

The Case Management approach has gained popularity in recent years. Case Management involves an individual being provided with professional assistance to access the services, supports and resources documents in an individual plan. Case Managers come from a range of professions including nursing, occupational therapy, social work and psychology.

The Case Management approach has particularly been adopted by both social and private insurance companies, as it has been acknowledged as a very cost effective way to assist people who are on insurance related payments to re-enter employment.

The main challenge inherent within the Case Management system is the cost ratios involved. In other words, where an insurance company is facing a potential liability sometimes running into millions of euros, it is extremely cost effective to invest in case management hours to promote the independence of the individual and thus reduce the long-term liability of the insurance company.

In a non-insurance context in which the Department of Health or Social Services has responsibility for delivering on an individual plan, it is difficult to see how such an intensive approach can be justified. This is not because the cost of social protection for an individual in the long term can run into hundreds of thousands of euros across the persons' lifespan, but that currently within the public sector this type of return on investment calculation is not taken into account when budgeting resources.

A more appropriate approach might be to adopt the principles of Case Management within a system of information, advice and advocacy in which those who are capable of accessing resources on their own behalf should be supported to do so and those who are experiencing difficulty should be provided with individual advocacy.

VI. The EU regulatory and policy framework for social services and health services

VI.1 EU competence in health and social matters

The competence of the European Union to produce legislation depends on the competence given to it by the Member States in its founding treaties. Article 2 of the Treaty defines the promotion of social progress and a high level of employment as fundamental tasks of the Community. This is implemented through the provision of a broad range of social services in Member States, including social protection schemes, care services and services to promote social and labour market integration of individuals (including housing). In the context of this document health services are also included in the definition of "social services" for the sake of practicality. It should however be noted that within the health system "health services"² and "social care services"³ tend to be organised and financed separately. This does not only affect the efficient functioning of the health systems, but could also result in a different treatment of these two elements of the health system according to EU competition rules

According to the subsidiarity principle, defining and organising these services is, in principle, of the responsibility of the Member States (at national, regional and/or local level and/or delegated to the social partners, depending on the internal rules of distribution of competences within the Member State). To the extent that such services are considered as economic activities, the EU has the responsibility to ensure that they are delivered in conformity with the rules and principles of Community law. This does not imply any harmonising or EU level decisions on how such services should be organised. However, it does mean that diverse national and sub-national systems which have evolved in response to specific political and social circumstances for the promotion of social welfare, health, employment and education must comply with Community rules

While the specific competence of the European Commission in the fields of social welfare and health has been quite limited, and it continues only to have shared or supportive competence in these areas, the influence of EC Legislation has nevertheless been gradually and considerably increasing, mostly indirectly through the implementation of the Community rules on the internal market and competition.

VI.2 Definition and scope of health and social services

- ***Social services***

There are two main categories of social services:

- Statutory and complementary social security schemes, organised in various ways (mutual or occupational organisations), covering the main risks of life, such as those

² Diagnostic, curative, and primary and secondary medical care.

³ Long-term, rehabilitative, non-medical and sometimes palliative care

linked to health, ageing, occupational accidents, unemployment, retirement and disability

- Other essential services provided directly to the person. These services that play a preventive and social cohesion role consist of customised assistance to facilitate social inclusion and safeguard fundamental rights. They comprise, first of all, assistance for persons faced by personal challenges or crises (such as debt, unemployment, drug addiction or family breakdown). Secondly, they include activities to ensure that the persons concerned are able to completely reintegrate into society (rehabilitation, language training for immigrants) and, in particular, the labour market (occupational training and reintegration). These services complement and support the role of families in caring for the youngest and oldest members of society in particular. Thirdly, these services include activities to integrate persons with long-term health or disability problems. Fourthly, they also include social housing, providing housing for disadvantaged citizens or socially less advantaged groups. Certain services can obviously include all of these four dimensions.

- **Health services**

As there is a general trend towards a holistic approach regarding health and health care, it becomes more and more difficult to make a clear distinction between health care services and other care services. It is to be noted that many health care professionals are now working for social service providers and that many non-medical professionals work in health care settings. Although, the EC has decided that health care services should be excluded from the *SSGI Communication*, it has not made a clear distinction between health care services and other care services. In the *Services Directive*, however, health care services are defined as healthcare and pharmaceutical services provided by health professionals to patients to assess, maintain or restore their state of health.

This separation of health and social services has confused providers and users of services alike, and risks creating an incoherent approach to the future provision of high-quality SSGIs and HSGIs. According to social NGOs, the European Commission should officially clarify why it chose to follow this separation and, if this separation is not reversible, should state how it nevertheless will in future ensure a coherent approach to SSGIs and HSGIs. Coherence between the two areas is important, not least in order to ensure the efficiency and the cooperation of the two sectors to ensure best quality for users.

VI.3 Social services as services of general interest

- **Characteristics of services of general interest**

Public services - known in European Union jargon as “*Services of General Interest (SGIs)* or *Services of General Economic Interest (SGEIs)*” - fulfil people’s daily needs and are vital to their well being. The quality of citizen’s lives depends on these services, which are essential for sustainable economic development and social and regional cohesion in Europe. Examples of SGI include as essential services such as water supply, gas, electricity, postal services, transport as well as social and health services. They all pursue two main objectives: implement fundamental social and economic rights of people and achieve economic, social and territorial cohesion. For this reason social NGOs regard

universal access to public services to be a fundamental right, and a pillar of the European Social Model.

Consequently, SGIs have a social mission, and play a key role in the realisation of fundamental rights (including economic and social rights) and in the promotion of social cohesion and inclusion. However the realisation of these social objectives very much depends on the quality of the services provided. Services which are not accessible equally to all or are not affordable to people with low income or which do not respond to individual's needs do not fulfil their social mission. SGI should be based on the following quality principles, which are essential for the realisation of their objectives: equality, accessibility, affordability, safety, proximity, continuity, transparency, universality and participation.

- ***The specificity of Social and Health SGI***

Social and Health Services of General Interest differ from network SGI like transport services or electricity supply services. They are indeed based on a complex interaction between the providers of such services and the beneficiaries. The beneficiaries of these person related SGI are characterised by their vulnerability and often their dependency on these services. The trust in the relationship between providers and beneficiaries is therefore important for these person related SGI. The specificity of social and health SGI lies also in the fact that they are an indispensable element of social protection systems.

In addition to the general principles applicable to all SGI, social and health SGI, to be able to fulfil their mission, need to be human needs' and human rights' centered, protective, user-empowering and conceived and delivered in a holistic approach in relation to the user and his/her needs. The freedom of choice of the user could be considered as another essential quality principle for social and health SGI. User choice however should not be the only objective. It should be part of an overall quality scheme for person related SGI which must guarantee genuine access and affordability.

Although under Community law, social services do not constitute a legally distinct category of service within services of general interest, the specificity of social services in relation to other services of general interest was highlighted by the Commission Communication "Implementing the Community Lisbon Programme: social services of general interest in the European Union". This communication defined some additional characteristics of social services:

- They operate on the basis of the solidarity principle, which is required, in particular by the non-selection of risks or the absence, on an individual basis, of equivalence between contributions and benefits,
- They are comprehensive and personalised integrating the response to differing needs in order to guarantee fundamental human rights and protect the most vulnerable,
- They are mostly not for profit and in particular to address the most difficult situations and are often part of a historical legacy.

VI.4 Social services as an economic activity

- **The relevance of the distinction between economic and non-economic activities**

The distinction between services of an economic nature and services of a non-economic nature is important because they are not subject to the same rules of the Treaty. For instance, provisions such as the principle of non-discrimination and the principle of free movement of persons apply with regard to the access to all kind of services. The public procurement rules apply to the goods, services or works acquired by public entities with a view to providing both services of economic and non-economic nature. However, the competition and State aid rules of the Treaty only apply to economic activities (i.e. "services" carried out by "undertakings" in the sense of the competition rules). The rules on the freedom to provide services, the right of establishment applies only to services which are economic activities.

- **Definition of an 'economic activity'**

Generally speaking, recent case law confirms that the concept of economic activity encompasses "an activity which consists in offering goods or services on a given market"⁴. The presence of an element of solidarity, the pursuit of social objectives or the nonprofit nature of the provider do not rule out the possibility of carrying out an economic activity. Some operators may agree to take aspects of solidarity into account in the light of other benefits they may obtain from intervening in the sector under consideration. Conversely, non-profit-making entities may compete with profit-making undertakings and may, therefore, constitute undertakings within the meaning of Article 87 of the EC Treaty. As a general rule, Community case law classifies as an undertaking any entity engaged in an economic activity, regardless of its legal status and the way in which it is financed⁵.

It should also be noted that an entity carrying out primarily non-economic activities may be engaged in secondary activities of an economic nature. In such cases, classification as an undertaking within the meaning of the competition rules will be confined to the economic activities involved. As a general rule, it is not possible to envisage compiling a list of activities that would not a priori be economic. The concept of economic activity is an evolving concept linked in part to the political choices of each Member State. Member States may decide to transfer to undertakings certain tasks traditionally regarded as falling within the sovereign powers of States. Member States may also create the conditions necessary to ensure the existence of a market for a product or service that would otherwise not exist. The result of such state intervention is that the activities in question become economic and fall within the scope of the competition and internal market rules.

- **The qualification of health and social services**

The Court has confirmed in several cases⁶ that *basic compulsory social security schemes* resting on the principle of national solidarity do not constitute economic activities. On the other hand, *supplementary social security schemes* can however constitute economic activities⁷.

⁴ See amongst others Cases C-180/98 à C-184/98, *Pavlov e.a.*

⁵ See in particular Case C-41/90 *Höfner and Elsnér*, and C-309/99, *Wouters*

⁶ See in particular joined cases C-159/91 and C-160/91 *Poucet and Pistre*, and , case C-218/00, *Cisal*,

⁷ In particular Case C-244/94, *FFSA*, Case C-67/96, *Albany*, joined Cases C-115/97 to C-117/97, *Brentjens handelsonderneming*. and Case C-219/97, *Drijvende bokken* .

In the *health sector*, one has to take into account on the one hand the provision of health services, which is to be considered as an economic activity and on the other the bodies financing and organising the health service provision. The latter are considered of not being of an economic nature when these organizations involved in the management of the public social security system fulfill an exclusively social function and perform an activity based on the principle of national solidarity which is entirely non-profit-making. But even if these functions make that these bodies do not constitute undertakings within the meaning of Articles 81 EC and 82 EC, the possibility remains that, besides carrying out these "social functions" these same bodies engage in operations which have a purpose that is not social and is economic in nature. In that case these operations could be regarded as activities carried out by undertakings or of associations of undertakings. As concerns the health services as such, the Court ruled at several occasions that these have to be considered as being economic activities even if the institution providing the service is not an enterprise in the sense of EC competition rules as outlined above.

The field of *social care services* differs enormously from Member State to Member State. Up until now the Court has ruled only in relation to private enterprises operating homes for elderly and concluded that this activity constitutes an economic activity within the meaning of the Treaty⁸. Nevertheless it held that a legislation making admission of private operators of homes of elderly to a social welfare system subject to the condition that the relevant operators were non-profit-making was compatible with the Treaty.

As far as *vocational rehabilitation* is concerned, the Court ruled⁹ that job placement services are economic activities and that the public institutions offering such services are undertakings.

Offering cheaper *housing*, through rents and construction loans, to certain consumers is to be considered as an economic activity. In a decision from 2001¹⁰, the Commission has indicated that municipalities carrying out such activities are in doing so in competition with other operators in the housing market and therefore performing an economic activity.

VI.5 Application of internal market rules to health and social services

As services of economic nature, social services fall under the EC Internal Market rules concerning the freedom of establishment and the freedom to provide services. Recently, a Directive on services in the internal market was adopted (so-called Bolkenstein Directive) with the objective to provide a legal framework that will eliminate the obstacles to the freedom of establishment for service providers and the free movement of services between the Member States. The Services Directive aims to increase competition by eliminating restrictions on market access for service providers and by removing obstacles to the cross-border provision of services.

The directive addresses three issues:

- The first set of articles aims to remove obstacles to the freedom of establishment of service providers across Europe. To this aim the directive provides for administrative

⁸ Case C-70/95, *Sodemare*

⁹ Case C-41/90, *Höfner and Elser*, and C-55/96, *Job Centre*

¹⁰ State aid N 209/2001 – Ireland

simplification measures and establishes the principles that regulation of services must respect. In particular, it establishes that regulation has to be relevant and proportional to the policy aim pursued and cannot discriminate between domestic and foreign companies.

- Second, in order to facilitate trade in services, the initial proposal of the directive introduced the so-called “country of origin” principle, according to which a service provider would only be subject to the regulation of his home country. Under this principle, states would not be able to restrict the provision of a service by a company established in another Member State. Such a principle would certainly have helped to boost trade between EU states since companies would not need to abide by local regulations in order to provide a service in another country. Moreover, it would have created incentives for national governments to simplify their regulation in order to put every company in the market on equal footing to compete. As will be discussed in the next section, the “country of origin” principle was the subject of a great deal of controversy and was eventually removed from the directive by the European Parliament.
- Finally, the directive provides for a minimum level of harmonization for issues such as consumer protection and safety standards and for mutual cooperation between the different national authorities.

The directive was perceived as putting at risk the “European social model” by allowing service providers to cross borders without abiding by local labor and social regulations. Many of the wealthier member states saw in the document an open door to service providers from new member states where wages are lower and social protection systems less developed. Moreover, the state plays an important role in the provision of many services in Europe (e.g. local transport, utilities, education, and health services) and many perceived the Services Directive as an attempt to privatize such services while ignoring their social component and in the process reducing quality standards. As a consequence of numerous lobby actions from the social sector, health and social services were exempted from the scope of the directive. However, they still fall under the internal market principle (art. 86 of the Treaty), which has actually created a situation of legal uncertainty for providers and users in the sector.

VI.6 Application of public procurement rules to health and social services

Member states can provide social services directly – either on the national, regional or local level or they can entrust the operation of social services to the other organisations. In both cases, the public procurement rules apply, although such contracts are only subject only to the provisions of the public procurement directives on technical specifications and advertising of the award notice. In addition, the principles of equal treatment, non-discrimination, mutual recognition, proportionality and transparency need to be respected.

The principle of transparency means that, in the interests of any potential tenderer, an appropriate degree of publicity should be guaranteed permitting the opening-up of the service contract to competition and the monitoring of the impartiality of the award procedures. The principle of equal treatment requires that all Community undertakings should be able to bid for SGEIs under the same conditions. The conditions and criteria must be objective and applied in a transparent and non-discriminatory manner.

When applying public procurement rules to the selection of a service provider, public authorities can choose between awarding the contract to the cheapest tender or to the “most economically advantageous” tender. The latter require the public authority to specify in the tender documents the criteria, with their relative weightings, chosen for the evaluation of tenders, in order to identify which is the most economically advantageous. Therefore, the award criteria chosen by the contracting authority are very important and may include elements other than price, such as the quality of the service. Any failures or inaccuracies in the tender documents but also financial problems attributable to the winning tenderer (offer of a price below economic calculations in order to be the cheapest competitor) could endanger the provision of the service.

VI.7 The application of state aid rules

State Aids are usually controlled by the European Commission in order to prevent the distortions in the internal market and to avoid unfair competition which would be a violation of articles 87 ad 88 of the EC Treaty. In this context, the European Commission must be always informed in advance and give prior approval about the schemes of State Aids at national level. There are just some few exceptions when the European Commission does not need to be informed. These exceptional circumstances are regulated through the General Exemption Regulations, where the European Commission formulates strict conditions under which states can freely provide aid to support their national policies and actors in the internal market. One of the exemption Regulations No 2204/2002) affects the field of employment. This Regulation stipulates the conditions on which State Aids, supporting recruitment and employment of disadvantaged and disabled people, could be provided.

The European Commission has decided to initiate a reform of all General Exemption Regulations in the field of State Aids in order to give more coherence to the regulations, to remove excessive barriers that were imposed on the countries and to prevent fraud on the distribution of State Aids. This new regulations are currently drafted and will be issued by May 2008.

VI.8 Other EU policy mechanisms and initiatives that impact on national disability strategies

Despite the fact that the European Commission has due to the subsidiarity principle very little competence in the disability field, it has developed some mechanisms and initiatives that in an indirect way substantially impact on the disability policies at national level.

- ***Open Method of Coordination***

In the context of rapid economic and social restructuring, the European Commission is particularly committed to making full use of voluntary cooperation methods which provide for adequate participation by all stakeholders: Member States, social partners, civil society, etc. This is notably the case of the Open Method of Coordination in the areas of employment, social inclusion, social protection and lifelong learning, which are crucial for people with disabilities and where the relevant common objectives can be translated into national policies and practices.

The existing OMC's in the fields of social inclusion and pensions, and the process of co-operation in the field of health and long-term care, have been brought together under common objectives and simplified reporting procedures. The overarching objectives of the OMC for social protection and social inclusion are to promote:

- (a) social cohesion, equality between men and women and equal opportunities for all through adequate, accessible, financially sustainable, adaptable and efficient social protection systems and social inclusion policies;
- (b) effective and mutual interaction between the Lisbon objectives of greater economic growth, more and better jobs and greater social cohesion, and with the EU's Sustainable Development Strategy;
- (c) good governance, transparency and the involvement of stakeholders in the design, implementation and monitoring of policy.

- ***Anti-discrimination legislation***

Article 13 of the Amsterdam Treaty gives the European Commission the right to undertake appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation. Although it does not confer any direct rights to people with disabilities, this article is a landmark in the sense that it introduces for the first time 'disability' in the treaty, and recognizes at least implicitly that there exists discrimination of people with disabilities. Based on article 13, the European Commission issued in 2000 an EU Directive On Equal Treatment in Employment and Occupation. This directive, which also applies to the disability field, prohibits direct and indirect discrimination in all areas of employment. Moreover, it permits quotas and all other positive actions measures, and obliges employers to make 'reasonable' accommodations for people with disabilities.

- ***Community Instruments***

The European Commission can issue a set of documents that have no legal force, but still influenced the policy-making at national level. Green papers put an issue on the agenda and launch a public debate with all relevant stakeholders. White Papers translate the results of this debate in concrete proposals. Communications present formal viewpoints of the European Commission, and contribute as such to awareness raising and the dissemination of policy ideas. Resolutions have a recommendatory nature but are also not binding.

Over the last years, the European Commission has used these community instruments several times in the disability field, and influenced as such the debate at national level considerably. Examples of such instruments include: the White Paper on Services of General Interest; the [Green Paper on Equality and non-discrimination in an enlarged European Union](#); the Communication on the Situation of disabled people in the enlarged European Union; the European Action Plan 2006-2007 and Council Resolution on promoting the employment and social integration of people with disabilities.

- **Funding**

The European Commission has in a consistent way used its huge funding resources to stimulate developments in the disability sector at national level. First of all, the European Commission included accessibility conditions in all its public tenders and funding programmes, and mainstreamed in this way an important disability issue throughout various sectors. Secondly, the European Commission directly funded the development and piloting of new disability services and initiatives via the financing of numerous projects (European Social Fund, Progress Programme, Lifelong Learning).

Finally, the European Commission financed some studies in the disability field to move items forward on the agenda at national level. Examples of such studies include: "Study on the specific risks of discrimination against persons in situation of major dependence or with complex needs"; "Study on multiple discrimination in the European Union" and "Study on compilation of the Disability statistical data coming from the administrative registers of the Member States" and "Study on the situation of women with disabilities in Europe in light of the UN convention on the Rights of People with Disabilities."