QUALITY IN HEALTH & SOCIAL CARE SERVICES FOR PEOPLE WITH DISABILITIES

POLICY & PRACTICE REPORT

THE PROJECT PARTNERS

C O N T E N T S

INTRODUCTION

The project "Health and Social Care Services for People with Disabilities - Quality Indicators". is a transnational project comprising nine partners from eight countries, funded by DG Employment and Social Affairs, European Commission, under the Transnational Exchange Programme 2003-2005, Community Action Programme to Combat Social Exclusion.

The objective of the project was to look in depth into the subject of service quality in public social services for people with disabilities; develop service quality assessment tools; and test these tools in a variety of different service provision settings in four countries. Its aim was to develop service quality assessment tools of generic value; that is tools that could be applicable across a broad range of public social services - not just the specific types of disability services service and service settings used for the development and testing of the assessment tools.

Defining service quality and assessing service quality is a complex and problematic task. It may involve a range of different approaches that are not always complementary, depending on the purpose of the assessment and its use; the standpoint and interests of those who conduct the assessment; and the way those who conduct the assessment understand the service itself and the roles of the different stakeholders involved - management, staff, clients, and any third parties involved.

In the project, service quality was defined and its assessment approached in a way that involves all relevant stakeholders, within the service and in its social and policy environment; and empowers to service clients by giving them a central position in the assessment of quality. The project approach treats the assessment of service quality as a task that should be initiated at the level of the service provision organization; be tailored to its particular conditions; and respond to the needs and interests of those directly involved - not as a task imposed or directed from above.

Therefore, the primary value of the project results concerns quality assessment at the level of service provision and it is chiefly targeted to stakeholder groups at that level. These groups include the management and the staff of service provision organizations who are interested in introducing quality assessment into their operations; and service clients or their representative organizations that may initiate, collaborate in, or respond to service quality assessment. Less directly, the project results may also be of value to stakeholders at the level of policy-making or service regulation who may want to promote and encourage initiatives for service quality assessment at the service provision level and encourage client involvement in the assessment of service quality.

Clearly, the quality assessment tools developed by the project can be more readily used by service provision organizations similar to those covered by the project and by organizations providing services to people with disabilities; but can also be adapted to other client groups and public service organizations in the broader social public services field. These tools are available in the form of a Service Quality Assessment Guide, through the website of the project, www.quality-disability.net, where all the materials produced by the project can be found.

This report is organized in two parts beyond this introductory chapter. In Part I, the issues of exclusion, service quality, and disability services are discussed. In Chapter 1, Yvonne Giedenbacher and Michael Stadler present an overview of the main concepts that inform this project; they discuss the definitions of disability, the relation between disability and exclusion, inclusion policies for people with disabilities, and quality in disability services. In Chapter 2, Jane Pillinger puts forward a policy framework for socially inclusive services for rethinking service quality in Europe. In Chapter 3, Steen Bengtsson discusses in depth the issues of service quality and policy for quality in the context of disability services.

In Part II, Nikos Varelidis presents the project approach and its experience in developing quality assessment tools for disability services. Chapter 4 presents the focus and concepts of the project. Chapter 5 presents the pilot application of the quality assessment tools developed, their results and lessons learned.

MOTIVACIO Office

Part I: SERVICE QUALITY IN DISABILITY SERVICES: THE POLICY AND PRACTICE CONTEXT

C H A P T E R 1.

DISABILITY, INCLUSION AND SERVICE QUALITY: AN OVERVIEW

1.1 Definitions of disability

Socio-economic and political concern about disablement has increased considerably in the last years and traditional approaches to and definitions of "disability" have been challenged in many ways and by various actors.

Very generally speaking, there are two different models in the discourse on disability. The medical model views disability as a problem of the individual, directly caused by disease, accident or some other health condition which is regarded as problematic. This view on disability is often referred to as the "personal tragedy theory" of disability (Oliver 1990). Essentially, the medical model is based on a deficit-oriented view of the individual. First, disability is regarded as a problem at the individual (body-mind) level; second, it is equated with individual functional limitations or other "defects"; and third, medical knowledge and practice determines treatment options. This approach leads to a very limited definition of disability not taking into account wider aspects of disability dictating "[...] a life as a passive "victim" characterized by social exclusion and disadvantage, and by dependency on assistance from family and friends and a "safety net" of state welfare benefits and services" (Barnes et al, 1999).

This medicalised view of disability was being challenged in the 1970s when disabled people themselves started to mobilize politically and gained increased visibility in the public arena. They shifted the focus away from the deficit-oriented picture of the "invalid" to disabling attitudes and barriers in various fields of their lives. This social model does not see disability as an inherent attribute of the individual, but as a product of the person's social context and environment. People with impairments are not disabled "in themselves" but by society and its failure to accommodate to their needs.

In 1980, the World Health Organisation (WHO) provided a very influential framework of disability (International Classification of Impairment, Disability and Handicap)

> *The "social model" does not deny the significance of impairment in people's lives but concentrates on those social barriers which are constructed "on top of" impairment [...] Instead of regarding disability as an individual limitation, the social model identifies society as "the problem", and looks to fundamental social and political changes to provide the "solutions". (Barnes et al, 1999, p.2f)*

introducing three different dimensions of "disability" (Impairment / Disability / Handicap). The main criticism brought forward not only by disability activists focused on this Classification's close relation to the medical model. Finally, the ICIDH was revised and the "International Classification of Functioning, Disability and Health" (ICF / ICIDH-2) is now the conceptual basis for the definition, measurement and policy formulations for health and disability and intended to be used as "[...] a planning and policy tool for decision makers." (WHO, 2002) The ICF sought to incorporate the "medical" and "social" models into a new "bio-psychosocial" approach. In addition, the classification assumes that functioning, activity and participation are influenced by a myriad of environmental factors, both material and social. (Barnes, 2003)

While the social model dominates the current discourse on disability among organisations of disabled people and theorists, the medical model still remains in a dominant position in social policy. Innovative approaches to the social construction of "disability" do not transform easily into administrative categories. (European Commission, 2002) The functional limitations approach is widely incorporated within legislation, assessment procedures and surveys of the prevalence of disability. By searching for exact, unambiguous, measures of disability, dividing lines and distinctions have to be made in a field where matters are extremely blurry and con-

stantly changing. Social policy agencies define disability by indicating boundaries and differentiating the boundaries between those crossing them and thus being disabled, at least temporarily, and those being outside these limitations and thus being non-disabled. Definitions used in anti-discrimination legislation in the Member Countries, for example, are usually very broad, whereas definitions used in social policy are more restrictive - and are often, at least implicitly, also based on various circumstances, such as the availability of adequate resources. This may lead to situations where "[...] people may be designated as disabled for one policy and not for another, and sometimes they encounter gaps in provision as a result." (European Commission, 2002)

Types of disability

The concept of "disability" or "disabled people" tends to create the impression of a homogeneous group. This impression is often misleading and does not come up to the diversity of concepts and definitions behind these terms (see discussion above) and the variety of situations faced by "disabled" people. One has to consider, that when making a categorization according to types of disability, this is usually done on the level of impairments, i.e. physical disability, mental disability, learning disability, sensorial disability. The knowledge of the type of disability is mainly regarded as relevant information for preventive and rehabilitative measures, but also for the development of skills profiles of the respective persons - it is very important to bear in mind that one specific type of impairment does not necessarily come along with one specific type of functional limitation.

However, to give a very rough overview of the different types of disability the following can be identified:

- Persons with intellectual / learning disabilities
- Persons with mental health problems
- Physically disabled people (including people with visual or hearing impairments)

Within this very heterogeneous group, only less than 10% are persons with inherent impairments/disabilities, more than 90% become disabled during their life course. An OECD study shows that disability prevalence increases considerably with age: 25% within the age group 50-64 and 10% within the age group 20-49 are disabled. (OECD, 2003).

1.2 Disability and exclusion

As described above, there are different possibilities to define "disability" and the boundaries between "non-disabled" and "disabled" are often blurred. For this and other reasons, data on disability, especially comparative data, has to be treated with caution. In the European Union, approximately 16% of the working age population consider themselves to have a longstanding health problem or a disability. This number is survey-based and not based on administrative data. (European Commission, 2005) Obviously, there is a strong correlation between disability and increasing age which means

Playground facility for disabled infants

that, given present demographic trends, the proportion of disabled people will increase considerably in the future. Thus, disability can be regarded a major issue affecting a significant part of the European population. However, the situation of disabled people is still less favourable than that of non-disabled persons and characterised by marginalisation and social exclusion.

"Social exclusion" can be defined in different ways and has various facets. In the Joint report on social inclusion it is defined as follows:

"Social exclusion is a process whereby certain individuals are pushed to the edge of society and prevented from participating fully by virtue of their poverty, or lack of basic competencies and lifelong learning opportunities, or as a result of discrimination. This distances them from job, income and education opportunities as well as social and community networks and activities. They have little access to power and decision-making bodies and thus often feeling powerless and unable to take control over the decisions that affect their day to day lives." (Council of the European Union, 2004)

Data from ECHP (European Commission, 2001) encompassing the EU-14 (EU-15 excluding Sweden) before the Enlargement show that those with a self-reported disability are less well-off than non-disabled persons. In the survey, 85.5% of the EU-14 population do not report a disability, 14.5% report a disability (4.5% severe disability" / 10% "moderate disability"). Level of education, activity status and social contact with friends and relatives represent key aspects of the disability profile.

- Education: Among those reporting a severe disability, 58% have not completed the second stage of secondary education, against 41% of those who report no disability. Persons with a severe disability are little more than half as likely as persons with no disability to have reached the third level of education (9 and 18% respectively). The age effect has to be considered in this context. A standardisation on a common age structure highlights the smaller likelihood that people reporting a disability will reach the third level of education in young

ages compared with persons not reporting a disability (European Commission, 2001)

● Activity status: In the age range from 16 to 64, 62% of those reporting no disability, 46% of those reporting a moderate disability and 24% of those reporting a severe disability are in work. Almost 70% of those reporting a severe disability and somewhat less than half of those reporting a moderate disability are inactive; among those reporting no disability, 30% are inactive ("raw" activity status = self-reported activity status). Also in terms of unemployment, a difference can be observed: 7% of non-disabled and 10% of severely disabled persons are unemployed. "Thus, when focusing on the most common activity period of life, the proportion of inactive persons is nearly three times higher among those with a severe disability than among those with no disability." (European Commission, 2001, p.29) There is not only a tendency towards vertical segregation (disabled people are more likely to work in less-skilled and lower-paid jobs) but also evidence regarding horizontal segregation (disabled people over-represented in specific occupations or in sheltered workshops). (Barnes et al, 2003)

● Social contact with friends and relatives: Regarding the frequency of interaction with friends or relatives, it appears that disabled people are more isolated than non-disabled: there are more than twice as many people who meet their relatives less than once or twice a month in the population reporting a severe disability than in the population reporting no disability. However, a standardisation on the age structure narrows the gap between those reporting a severe disability and those reporting no disability, but a gap remains. (European Commission, 2001)

In summary, compared to people who do not report a disability, those who do report a disability are less likely to be married and more likely to never have been married, have less chance of attaining the highest levels of education and are more likely not to complete their studies. They also have a lower probability of working, and those who do work are less likely to work full-time. They are more often in blue-collar occupations and somewhat more often in the agricultural sector. Their source of income is less likely to be earnings and more likely to be a pension or benefit, for example, sickness and disability benefit, but they are less likely to have no personal income. (European Commission, 2001)

Despite certain developments in social policy regarding disabled people, they still experience marginalization: "Irrespective of where the spotlight has been directed [...], disabled people, compared with their non-disabled counterparts, show a clear pattern of restricted life chances, choices and opportunities for social participation." (Barnes et al, 2003)

1.3 Disability and inclusion policies

In the Joint report on social inclusion (Council of the European Union, 2004) "social inclusion" is defined as follows:

Social inclusion is a process which ensures that those at risk of poverty and social exclusion gain the opportunities and resources necessary to participate fully in economic, social and cultural life and to enjoy a standard of living and well-being that is considered normal in the society in which they live. It ensures that they have greater participation in decision making which affects their lives and access to their fundamental rights (Council, 2004).

The EU commits itself to a "new approach" to disability, which is mainly an equal rights approach, based on the fight against discrimination and the promotion of the participation of disabled people into economy and society and stresses that "[...] boosting equal opportunities for people with disabilities goes beyond integration through employment" (Commission of the European Communities, 2003)

The discourse on "social inclusion" was very much shaped in the 1990s, parallel to three major challenges to existing disability policies and provisions:

● The high levels of expenditure on disability benefits posed a threat to the sustainability of income maintenance systems. Therefore, governments tightened up benefit schemes and emphasised strongly active employment measures for disabled people.

● Heavy criticism on the traditional conceptualisation and definition of disability in the public policy sphere was brought forward mainly by disability activists.

● Disabled people's organisations became more and more visible and active in the public arena, thus acting as pressure groups on behalf of themselves. (Oorschot et al, 2001)

As a consequence of these challenges, disability has become a major issue on the European agenda and the EU has issued several statements and publications on disability policy. The European Action Plan 2006-2007 (Commission of the European Communities, 2005), for example stresses the fact that disabled people should have the same individual choices and control in their everyday life as non-disabled people; the basis for this being an environment that enables disabled persons to be more independent. Four priorities are set to promote the independent living of disabled Europeans:

● Encouraging activity (i.e. employment integration)

● Promoting access to quality support and care services

● Fostering accessibility to goods and services

● Increasing the EU's analytical capacity (i.e. improvement of data availability)

Daily Assistance Service Office

The National Action Plans for Social Inclusion (NAPs/inclusion), generally broad in scope, identify risk factors associated with poverty and social exclusion (e.g. long-term unemployment, low level of educational attainment or housing problems). Disability is one of those risk factors described in the National Action Plans. However, the relation of various measures and provisions with disabled people remains a little unclear. The Joint Report on Social Inclusion comes to the conclusion that

Even if all Member States recognise in the NAPs/inclusion that disability appear as a determinant of poverty and exclusion, it should be noted that only some Member States have included a specific reference to people with disabilities under the section "challenges". Disabled people are mainly included in the "disadvantaged" category. Therefore, it is unclear where certain measures for "vulnerable" groups apply to people with disabilities. Nevertheless, most Member States included in their NAPs/inclusion a considerable amount of policies and measures for people with disabilities in chapter 4 (strategic measures) [...] (Council of the European Union, 2004).

The authors of the Joint Report summarized four main policy approaches to social inclusion of disabled people mentioned in the National Action Plans:

• Member states take a civil rights approach to disability

• Positive trend towards accessibility policies for the provision of goods, services and infrastructures

• Promotion of social inclusion through employment of disabled people

• Promotion of provision of long-term care and assistance at home or in the family

The Joint Report also concluded that, although it is more and more acknowledged that social exclusion goes beyond unemployment, the effects of disability have not been sufficiently addressed by some Member States in key policy areas (e.g. education, training, information society, care, housing, transport, participation in culture and sports) (Council of the European Union, 2004)

1.4. Quality in disability services
Services for disabled people and the quality discourse

Service providers respond to the needs of over 50 million disabled people in Europe. The field of services for disabled people is very diverse - regarding their target groups (e.g. persons with visual impairments, mental health users) and the type of service they actually provide (e.g. day centres, supported employment, job coaching, transport services...). Services for disabled people are Social Services of General Interest (SSGI) and share common values based on the recognition of fundamental rights and their general principles (e.g. universality, accessibility, affordability).

The European Association of Service providers for Persons with Disabilities (EASPD) has summarized the specific characteristics with distinguish SSGI and especially those services related to the disability field from other Services of General Interest (e.g. network industries). There are two levels of these characteristics:

• Level of relation with the client, e.g. importance of interpersonal relationship between "supplier" and "client"; disabled people are supported to enhance their personal development and their participation to society; relationship between "supplier" and "client" is based on fundamental rights; need for an individual approach to each - very individual and specific - question.

• Level of the organization, e.g. mainly NPOs; service providers contribute to social cohesion in the community; not-for-profit actors are laboratories for social development and renewal (EASP, 2005).

The issue of "quality" in services for disabled people is very much related to ideas of user choice, user involvement and user empowerment as major structural prerequisites and/or outcomes of quality services. Two major developments have led to this focus: The first dates to the 1970s, when a different picture of disability was emerging, brought forward by disability activists in a bottom-up way (shift from the medical to the social model of disability, see 2.1). The driving force of this development was to achieve equity, autonomy and quality of life for people with disabilities. This meant a major challenge, not only to the personal social services dealing with people with disabilities but also to national disability policies in general. The second development was the adoption of business models of management in the area of personal social services and the neo-liberal critique of public monopolies both of which brought a new focus to the user of services as being the "consumer" of the services instead of being their "client". People with disabilities sought to exploit these new opportunities of consumer choice stemming up from this new model and use them in order to achieve greater autonomy over the services provided for their supposed well-being.

However, it has to be considered that social services do not have consumers in the business-sense. The services are much more based on the interaction between the "carers" and "those receiving care". This perspective shifts the focus again away from the "consumer" to the "co-producer" of a service. The two developments as

depicted above are part of a crisis of the welfare state in general, of which there are at least three dimensions:

• a crisis in the welfare state in that it was not meeting social needs,

• a crisis in the welfare state in that it was creating needs that it could not meet,

• a crisis by the welfare state because of rising costs (Oliver, 1990).

Approaches to service quality and its assessment

Very generally speaking, two approaches to service quality can be identified: business methods (establishment of quality standards, e.g. ISO 9000; benchmarking; general methods encompassing the entire organisation, e.g. Total Quality Management) and traditional professionally-based methods (such as peer review) (Bengtsson, 2002). Evers extends this collection of approaches by bottom-up models for new service relationships based on both individual and collective citizen and consumer control and participation and by "inspectorate approaches" sometimes executed by people from the same professional field and based on the process of laying down "general standards" (Evers, 1997) Whereas the professional approaches are mainly concerned with producer quality, business approaches tend to focus on consumer quality. Both quality regimes can have major drawbacks, as Pollitt describes:

Producer quality can degenerate into a situation of cosy connoisseurialism in which senior members of a profession or expert group exercise great influence without having to justify their judgements in terms of any transparent or evidence-based criteria [...] Business approaches, by contrast, can quite easily decay into a from of managerialism where managers manipulate consumers in order to enhance their own control over other staff. (Pollitt, 1997)

Both concepts can often be criticised for not integrating service user's view adequately into the process of quality definition and assessment. In the first quality regime (professional models), the agenda is set by professionals who may be blind to unequal power-relations and may feel threatened by service users who challenge the received wisdom of the professionals. Within the second quality regime (business models), the issue of "consumer satisfaction" does very often not grasp the emotional element in service "delivery", which is based on the interpersonal relationship between service staff member and service user. Furthermore, consumer satisfaction is usually tapped with satisfaction questionnaires where the agenda is set by managers and not be service users. Some attempts at project or at national level have been made to overcome this problem of agenda setting by gatekeepers:

• The basic idea of the QUIP project ("Quality in Practice: Stakeholders" view of Supported Employment"),

was that the quality of Supported Employment for disabled people depends on functioning partnerships between the different stakeholders in the process: service users, service staff, service managers, employers and funding agencies. The aim was not to assess the quality of the services on the basis of set quality criteria but to define quality criteria based on the views of the different actors. The quality assessment and evaluation tools were then designed on the basis of these results (Giedenbacher et al, 2003).

• In the White Paper Valuing People, the British Government formulates the objective that they want "to ensure that all agencies commission and provide high quality, evidence-based and continuously improving services which promote both good outcomes and best value. This strategy for people with learning disabilities aims to measure quality based on the best quality research, develop benchmarks for performance measurement and have the needs of the service users at the centre of the quality assurance system. People with learning disabilities and their carers should be fully involved in planning, monitoring and reviewing and evaluating services they receive (Department of Health, 2001).

The National Action Plans on Social Inclusion hardly deal with the issue of service quality in a holistic approach, but discuss mainly accessibility issues - also in relation to demographic changes and the increasing numbers of those suffering from mental health problems:

Ensuring the provision of quality services which are adequate, accessible and affordable for all citizens is still a major challenge for some Member States. In particular, the challenge of increasing access to health services and care services especially for the elderly and the mentally ill or suffering as well as the importance of access to transport are given a new prominence in many NAPs. (Council of the European Union, 2004)

RETHINKING THE QUALITY OF SERVICES IN EUROPE: A POLICY FRAMEWORK FOR SOCIALLY INCLUSIVE SERVICES

2.1. Introduction and theoretical context

This chapter examines the policy context for the development of improved quality of services for marginalised groups, with a particular emphasis on user-focussed services for disabled people. It presents a framework based on a model of equality and social inclusion, and user orientated services through new methods of user participation. This is particularly important in the context of the development of health and social services to support independence, autonomy and rights for disabled people.

The objective of this chapter is to develop a better understanding of the ways in which good quality services for disabled people can promote independence and participation in society based on the twin principles of equality and social inclusion. In particular, this raises questions about what rights and duties on public bodies are associated with the provision of good quality services, and, therefore, what rights, principles and values should underpin and shape future social policies and health and social care provision for disabled people in a national and European context.

As social and economic problems have become more complex and multifaceted, so have the risks of social exclusion. Tackling these problems requires different approaches to public financing, service delivery and the production of welfare. The risks of exclusion and marginalisation are further exacerbated where there are difficulties in accessing services and deficits in services and service exclusion. People will be at greater risk of marginalisation if they live in poverty, in isolation, in rural areas, have weak family and social ties, in areas of high unemployment and where there are low employer incentives.

European Union policy also emphasises the need for access to employment for excluded and marginalised groups to be based on multifaceted strategies, including the promotion of equality and quality employment. The focus on marginalised groups can be seen in the policy areas of employment, anti-discrimination and social policy/social inclusion with the emphasis, since the Lisbon Economic Council, on the need for more and better jobs and increasing attention to anti-discrimination and social inclusion.

Vocational training in biological farming

2.2. A focus on social inclusion

What is social exclusion?

Poverty and social exclusion take complex and multi-dimensional forms which require the mobilisation of a wide range of policies under that overall strategy. Alongside employment policy, social protection has a pre-eminent role to play, while the importance of other factors such as housing, education, health, information and communications, mobility, security and justice, leisure and culture should also be acknowledged. (European Council, 2000).

Social exclusion can take many forms and results from a combination of problems such as unemployment, poor skills, low incomes, bad housing, poor mental and physical health, social isolation and family breakdown, and poor access to services. In practice this relates to:

• Poor access to services such as education, work and health; a lack of access to services can impact negatively on health and well-being. For example, poor access to services for people with disabilities can reduce the capacity for people to fully participate in society and there can be an overall negative impact on health and well-being as a result.

• Limited social networks such as local communities or families; this is particularly relevant to the north; west where there are high levels of rural and social isolation.

• Lack of participation in decision-making in areas that impact on a person's life; this can include decision-making about an individual's health care through to participation and involvement in the design, delivery and monitoring of health services.

• Many people are excluded because they experience poverty; poverty in turn impacts on a person's ability to participate effectively in economic, social, political and cultural life.

• Some individuals or groups experience stigma and discrimination because of their identity or status.

As a result it can be argued that there are four main aspects of social exclusion:

• Exclusion from civil society: exclusion from participation because of culture, institutional mechanisms or discrimination e.g. minority ethnic groups, Travellers, disabled people, older people etc.

• Exclusion from social goods: exclusion for services

and a failure to meet people's service needs in areas such as health, housing or education

• Exclusion from social production: lack of opportunities to contribute to and participate in society, this could be because of social isolation that results from living in a rural area

• Economic exclusion: exclusion from and poor of access to training and employment

It can be argued that there are primary social relations of inequality related to class, race, ethnicity, religion, age, disability and sexuality and that there are secondary social relations of equality resulting from employed/unemployed, dual earner/non earner households, two parent/lone parent households, house owner/renter etc.

The different elements of the multifaceted nature of social exclusion can be found in Figure 1.

Figure 1: The multifaceted nature of social exclusion
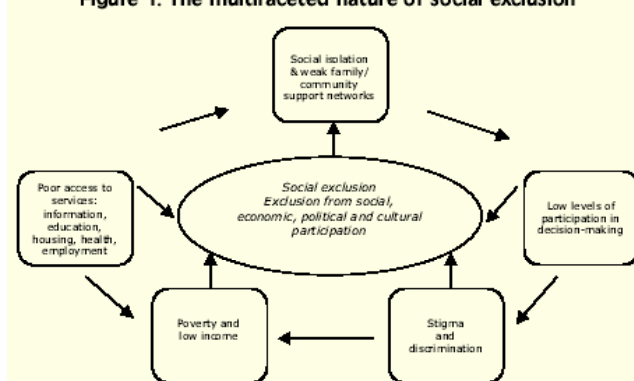
2.3. The disability policy context and the social model of disability

Theoretical frameworks and models of disability

Research on the experience of disability shows how disability is being determined by the social, material and cultural world in which people finds themselves. Disability in this context is the result of prejudicial actions and discriminatory practices and environments. As a result people with impairments are disabled by society. As a result the paper uses the general term "disabled people" rather than "people with disabilities" in order to recognise the social and cultural ramifications of disability (Oliver, 2002).

The two main models of disability are the medical model and the social model, although the medical model continues to be the dominant model in Europe. The medical model relates health status to individual physical, sensory, intellectual, mental health conditions and individual health conditions. This has been challenged by the disability movement as individualistic and reinforcing dependence and exclusion. The social model of disability, which grew out of the international

disability rights movement, stresses the importance of understanding how health status relates to impairment and disabling social environments, rather than the person's impairment.

The social construction of disability

This disability movement, which began as a civil rights movement initially in the USA and now present in most European countries has argued that the relationship between the provider of services and the receiver of services is located in the social relations of power and inequality, is based on a critique primarily directed at care provision in health and welfare services as well as other services with which disabled people engage. This critique asserts that disabled people have been denigrated, medicalised, patronised, isolated and rendered dependent. In particular the medicalisation of disability has associated impairment with sickness and pathology in comparison to able-bodiedness as health and normality. This has resulted in the social construction of disability as deviant, vulnerable and dependent, resulting in a focus on the impairment rather than the person. The disability movement and the associated growth of the Independent Living Movement has

pressed for choice, empowerment, support and independence for disabled people as alternatives, within a framework of a social model of disability, citizenship and rights (Williams, 2001; Shakespeare, 2000; Morris 1993; Sevenhuisjen, 1998).

The question posed in this chapter is how the knowledge and understanding of the social model of disability can contribute to enhancing the quality of service provision. This means having a better understanding of the processes and lived experiences of disability that need to be taken into account by policy makers and service providers.

Although rights to anti-discrimination and equality are a crucial element of citizenship and rights, disability organisations are increasingly arguing that their rights should include rights to and control over care, welfare and other services. In particular, the shift from "charity to rights" has been associated with independence (being able to control decision and choice affecting their lives as well as the capacity to carry out daily living tasks independently). In this respect care and welfare services have served to perpetuate hierarchies based on disabled people as being needy and dependent.

The social model of disability has increasingly framed thinking concerning the quality and provision of services for people with disabilities. It has been the basis for the creation of the UK's Disability Rights Commission and internationally, it has been incorporated into the World Health Organisation's (WHO) International Classification of Functioning (Bickenbach et al, 1999), which covers the areas of functioning and impairment, on the one hand, and contextual factors, such as environment and personal factors, on the other hand.

The experience of disability in Europe is summarised in Box 1.

Box 1: The experience of disability in Europe

• 17% of the population has a chronic illness or disability

• 15% of working age people have a chronic illness or disability

• 12% of the people have a work-limiting illness or disability

• 8-10% of the working age population has a significant chronic illness or disability

• 6% of working age people receive a disability related benefit

• There is an increased incidence of mental health difficulties in all EU countries

• There continue to be high rates of non participation of disabled people in the workplace

Source: Grammenos (2005)

Defining disability and the International Classification of Functioning

The ICF (International Classification of Functioning, Disability and Health) is a classification system for defining disability using a bio-psychosocial model based on definitions that are consistent nationally and internationally. Drawn up by the WHO in consultation with organisations representing disabled people, the classification is intended to provide a framework for international comparable statistical research on disability. In promoting a better and comparable understanding of disability, the ICF has been adopted by 191 countries as the international standard to describe and measure health and disability.

The classification has implications for the development of services for people with disabilities, social policy, for improving access to medical and social care, and for the protection of the rights of people with disabilities. An important aspect of the ICF is the account it takes of the social aspects of disability (WHO 2001). It provides a framework for the description of human functioning and the involvement of disability organisations in the process of revising and drawing up the ICF has helped to ensure that it has wide scope and validity.

Handicrafts workshop

The potential of the ICF is the importance of the relationship of the ICF to the UN Standard Rules on the Equalization of Opportunities and the recognition of the social construction of disability. For example in Ireland, the National Disability Authority has used the ICF as a framework for pilot study for the forthcoming Irish National Disability study in order to provide much needed baseline data on disability in Ireland, prevalence of disability (Good, 2003).

The disability policy context

Legislation and policy promoting equality and human rights for disabled people has been emerging over the last two decades. The UK and USA, in particular, have seen strong disability-rights movements that have lobbied for rights based approaches and the full integration of disabled people into work and society.

Disability legislation in the UK, USA and Canada have enforced public bodies to provide access to public services and public buildings for disabled people alongside robust anti-discrimination measures. Two notable example is the Northern Ireland Statutory Equality Duty, and the UK's Disability Discrimination Act, provide models of legally enforceable duties to promote equality, that require public authorities to be proactive in mainstreaming equality, auditing their functions and implementing new policies and practices.

International commitments and a rights based approach

There has been a growth of international human rights commitments that include the human rights of people with disabilities. The UN Standard Rules for the Equalisation of Opportunities for People with Disabilities were drawn up in 1993. There is no doubt of the importance of these international developments to the changing perceptions of disability internationally and the articulation of the rights of disabled people to full participation in society and a social model of disability. In some countries, for example, Sweden and Finland, the Standard Rules have been used as a framework for the development of disability policy (Pillinger, 2004).

There are also a number of international and European developments shaping a rights based approach to disability policy. In the EU this can be seen in the focus on social exclusion of disabled people in the National Action Plans on Poverty and Social Inclusion (NAPS Inclusion) and the focus on anti-discrimination in the EU Framework Directive on Employment[1]. The role of a broad ranging approach to disability policy based on a social model, is exemplified by the Madrid Declaration of the European Disability Forum in Box 2.

Box 2: European Disability Forum: The Madrid Declaration

The Madrid Declaration represents a vision developed at the European Congress on Disability welcoming the proclamation of 2003 as European Year of People with Disabilities. The Declaration sets out a framework for action at European Community level, national, regional and local level.

The preamble includes the following principles:

• Disability is a human rights issue

• Disabled people want equal opportunities not charity

• Barriers in society lead to discrimination and social exclusion

• Disabled people: the invisible citizens

• Disabled people form a diverse group

• Non-discrimination + positive action = social inclusion

The Programme for Action includes the following:

• Legal measures including comprehensive anti-discrimination legislation.

• Changing attitudes

• Services that promote independent living

• Support to families

• Special attention to disabled women

• Mainstreaming of disability

• Employment as a key for social inclusion

• Nothing about disabled people without disabled people.

The attention given to human rights and citizenship based framework can be seen in the United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (United Nations, 1993), a resolution on disability of the General Assembly of the UN (passed in December 2001) and the discussions that are currently taking place for a UN Convention on the Rights and Dignity of People with Disabilities. Similarly, human rights are enforceable through the European Convention on Human Rights and Fundamental Freedoms (1953) and the European Social Charter (1961)[2]. In the UK, for example, the implementation of the European Convention through the 1998 Human Rights Act has been important for disabled people on the basis that disabled people have the same human rights as other people. In the area of health this would mean addressing issues such as restriction of medical services, degrading treatment in residential care and prejudiced judgements.

Do disabled people have rights to services?

Rights based legislation that links human rights exists in Canada, the US, the Netherlands, the Nordic countries and the UK (Pillinger, 2004; Degener and Quinn, 2000). In some countries there is a right to legal redress. According to Degener and Quinn (2000) there has been a "...paradigm shift to the human rights perspective [which] is now nearly universal. Most countries are beginning to view disability as a human rights issue". There are a number of different approaches to the rights of disabled people. For example, in Germany, Finland and Canada provision is made in constitutional law, whereas in Britain, Sweden and Ireland provision is made in civil law, and in France in criminal law. A particular role is played by human rights legislation in the USA, UK, Canada, New Zealand and Australia.

In Canada and the Nordic countries, access to high quality health and social care sits alongside positive developments in disability rights and anti-discrimination policies. This highlights the importance of the dual impact of a well-funded, universal system of health care that provides a wide range of health and social supports for people with disabilities, alongside a civil rights framework that provides for a social model of disability and a rights based framework.

Many countries have outlawed discrimination against disabled people at work, however, this approach is more limited in relation to rights to health and social care services for people with disabilities. There are some rights based approaches to health and social welfare provision and the right to certain services for disabled people have been established in Sweden, Finland, the USA, Australia and Canada. In Sweden and Finland, there is a right to named services, including personal assistance and support. In Germany legislation introduced in 2002 on equality of treatment (Behindertengleichstellungsgesetz, BGG) has the goal of eliminating discrimination of disabled people to ensure their participation in society, the elimination of barriers and the provision of sign language. The legislation contains a right to action for associations/organisations of disabled people (who are significant service providers in Germany) if rights are violated, but not the right to action for individuals.

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1. *Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation. This is supported by an Action Programme to combat discrimination (2001-2006).*

2. *The European Convention on the Protection of Human Rights and Fundamental Freedoms draws its inspiration from the Universal Declaration of Human Rights, and principally covers civil and political rights, whilst social and economic rights were later developed through the European Social Charter.*

Rehabilitation through sport activities

2.4. Improving the quality of services

Defining quality services

The relatively recent focus on service quality particularly in areas such as health, social care and social welfare across Europe is a reflection of a more results and outcome based approach to public service delivery for customers/citizens and higher expectations of citizens for quality services (Pillinger, 2001). This sits within a framework of improving service quality in respect of citizen, client or customer orientated services.

Quality is a difficult issue to define and has been approached in a variety of different ways by different organisations. Public Service Quality has been introduced as a mechanism to reform and improve public services and is part of the new public management which has been characterised by changes in organisation and delivery of services, alongside changes in human resource management (OECD, 1996). Emphasis is on developing "service excellence" rooted in evaluation, quality management, client consultation and customer satisfaction surveys. At the same time the growth of consumer and user movements has led to pressure for improved service quality, and, in some cases, to "a range of counter-discourses in the politics of quality and consumption" (Rieper & Mayne, 1998).

Central to this process is the importance of service quality to strategic goals and objectives and for connections to be made in quality service between service delivery and policy development. Running through the process of change is the need for changes to be made in organisational culture away from meeting provider needs and priorities to meeting those of the customer. This requires changes in the ways that services are delivered, changes in the attitudes or assumptions that are made about different user or client groups, and changes in the value systems that underpin delivery. Fundamental to quality improvement initiatives has been the development of a variety of different models that connect with the citizen-client in order to improving service delivery (OECD, 1996).

Variations in perceptions of quality will also be guided by different expectations of what quality means to different stakeholders and how user expectations are met in practice, and by different social and political values attached to quality. This includes concepts of quality as excellence, quality as value, user perceived quality, quality as meeting user expectations, and quality as management. New approaches to quality emphasise user empowerment and these have been based on service delivery initiatives that stress transparency, participation, satisfying user needs and accessibility, with service quality initiatives that have forced the public sector to become more outward looking and client focussed. Strategies to improve quality are linked to the increased plurality of provision, market competitiveness and cost effectiveness, alongside mechanisms to improve the quality of services, their social acceptability and legitimacy.

The growth of activity in the area of quality range from simple quality statements to more sophisticated quality assurance mechanisms. At their best quality improvement in health, social and welfare services have helped to identify unmet needs, some of which have resulted in new services, whilst in others these have improved, were reoriented and developed the quality of existing services. Of interest is that the best quality services (as measured from the perception of the user who is receiving the services) are those that are decentralised with effective political accountability and with adequate resources, as well as coordinated and provided to people in their local communities. For people with disabilities, this is particularly important in the context of the move towards more community-based forms of care, independence and autonomy. These perspectives can challenge quality standards based on the traditional medical model of care so that they can shift to supporting wider social integration and independence.

A framework for quality services

There are a wide variety of quality initiatives now being driven by governments and international organisations impacting on health, social care and social service organisations. A key dimension missing from many of these is a wider framework and analysis of what constitutes quality. In this paper I argue that quality improvement measures should take place within broad and interlinked framework of:

- Equality and inclusion.
- User involvement and participation.
- New ways of organising and delivering welfare services, including the coordination and integration of service.
- Quality work (as well as work, working practices and professional development in the social welfare services).

These are presented in Figure 2. This framework is particularly important as needs have become more complex and as policy solutions have needed to be more imaginative, multifaceted and reflexive. All four areas are interrelated. If equality and inclusion lead to greater user involvement and participation - this will impact on the delivery of front-line services.

(i) The organisation and delivery of services

Improving the quality of services requires new thinking about the organisation and delivery of services. In particular improving the quality of services through the integration and coordination of services has been a major aspect of new service delivery reforms across Europe. The need to coordinate and integrate services is a policy objective associated with improving the quality, flexibility and responsiveness of the social public services to service users. Much of the change in thinking arises from an awareness of the rights of users, away from an approach of care and assistance towards an approach of support and empowerment, which brings the possibility of services being organised to promote autonomy, independence, agency and participation of users and to bring these to the forefront of policy discourses. Innovative reforms have been introduced in the social public services through the creation of entirely new services or by restructuring existing services. Devolution, decentralisation, deregulation and deinstitutionalisation have been features of these changes.

An important future challenge for health, social and welfare services will be the need to build on good practice and develop more systematic understandings of the point at which services need to be coordinated and integrated to allow for both tailored or personalised packages, alongside universal provision. Finding the balance between selective and universal services will be important to the future development of services.

Adapted appartment

(ii) User involvement, participation and empowerment

The involvement, participation and empowerment of users in quality improvement has become an increas-ingly important focus of service quality. Different levels of user empowerment, participation and involvement exist and these can be identified on a continuum of: information, consultation, partnership, delegation and control. Two particular types of user involvement exist: first, management-led user involvement which incorporate user perspectives and user feedback into service quality initiatives, for example, through surveys, and, second, user-participation or dialogue-orientated forms of user involvement, which directly involve users to influence policy, for instance, through empowerment evaluation, emancipatory research practice and co-decision making. These methods help to place the disabled person at the center of service provision by ensuring that the experience of disability is captured so that it results in real improvements in services for service users and improvements in material conditions. Examples of effective forms of user participation and empowerment can be found in user led approaches to policy development and service.

An important issue for users is the extent to which their voice is taken seriously, or whether pressures to develop user-orientated services means that professional ethics and interests take a priority over user needs. There is a danger that user empowerment could become a panacea that does not fully take into account the different meanings of empowerment for different groups of users. Associated with this is the problem that users could become incorporated into quality systems and organizational regimes that accommodate rather than empower them. An important related question is the issue of user choice in services and whether the welfare-mix really does promote choice in a liberal framework that may work against the development of rights to services. Choice is clearly an important feature of the demands for independent living in enabling users to choose their own personal assistant or carer. However, providing for choice in an open market place where a range of services may be on offer, could lead to confusion or lack of continuity in services for those users who are the most vulnerable or disadvantaged.

The different levels of power, knowledge and influence held by users and providers may make it difficult for users to participate on an equal footing and complex quality systems may also exclude users from full participation. An important further question is how user involvement can be integrated into feedback systems, mechanisms for restructuring services in the light of needs identified by users, and continuous quality development. The development of user organisations and empowerment strategies that build the capacity of

Figure 2: The dimensions of quality health, social care and social welfare services

(i) Organisation and delivery of services

QUALITY
Health, Social care and social welfare services

(iv) Equality and social inclusion

(ii) User involvement, participation and empowerment

(iii) Quality work

A rock band of disabled people playing

users will be important to fully develop user participation in practice.

There is now a greater emphasis now given to user consultation, including participation in the planning, development and monitoring of services. Much of this has resulted from the growth of disability user movements and networks of users and their associations. Despite a growth of initiatives on user participation and empowerment there remains limited evidence of systematic research to identify user needs. The bulk of the evaluation of services, including the quality of services, takes place from a provider perspective and methods of identifying user needs and preferences are not widespread.

However, the increasing focus on user's rights has had an impact on user participation and the creation of standards that include rights and participation, often developed within a framework of user empowerment. There are different levels of user empowerment, participation and involvement exist and these can be identified on a continuum of: information, consultation, partnership, delegation and control. Examples of different approaches to user involvement and empowerment can be found Box 3 below:

Box 3: Models of participation

There are a number of different elements of participation of service users:

• User friendly services: these offer limited forms of consultation; staff and management are in control of decisions.

• User centred services: users are at the centre of decisions about health services, whereby users are involved in the planning of services, although not necessarily the final decision-makers about services.

• User controlled services: services are provided directly by service users.

Consumer participation can also take place at a number of levels:

• At an individual level, consumers/users are able to participate in decisions about their own health care. Providing accessible information about services, having methods for control and participation in decisions is important.

• At the organisational level where there are a number of different methods of participation in influencing the planning, organisation and delivery of health care.

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

(iii) Quality work

Good working conditions are important to both the quality of service and for workers to have decent and satisfying work, with conditions of employment and pay that reflect the challenges and responsibilities that staff face. Decent working conditions, participatory forms of involvement in job design, work organisation and quality initiatives are directly linked to job satisfaction, motivation and health. In some areas of the health, social and welfare services staff retention and recruitment has become a problem associated with the low status accorded to jobs in the sector, and a significant issue has been the need to improve the image, status and professionalism of work within the health, social and welfare services.

Rehabilitation through sport activities

In a rapidly changing sector, innovation, coordination and integration require investment in human resources, including both staffing levels and continuous training. In addition, innovative, integrated and coordinated services require high levels of staff commitment, motivation, involvement and cooperation, along with new staff competence and awareness. A balance between flexibility and security is needed so that the commitment, cooperation, flexibility and the adaptability of staff are balanced with security of employment. Some of the uncertainties and insecurities amongst workers could be overcome with longer-term funding regimes and management systems that encourage participation in service restructuring and planning. In some countries the precarious nature of employment has worked against the sustainability of good practice and innovative projects.

Training is central to the development of new skills and new working practices brought about by coordinated working methods. There is clear a need for more coordinated approaches to training and development between providers and funding agencies in order to promote more coordination in services. Likewise, staff development programmes can help to improve quality and particularly the implementation of quality assurance procedures so that staff are on board and involved in quality development in ways that are meaningful and relevant to the service.

(iv) Equality and social inclusion

There are a number of different elements of a framework for equality and social inclusion. Key issues impacting on an equality and social inclusion framework for quality services are an awareness and understanding of social inclusion, action to reduce inequalities in areas such as health and education, equality of access to services, prevention and early intervention and addressing the risks associated with social exclusion, and coordination, integration and partnership.

Equality of access to services

This means giving recognition to people's different identities and status. In some cases ensuring equality of access to services means devoting greater resources to the needs of some groups in order to guarantee their equal access to services. Providing services that are efficient, effective, culturally sensitive, and equal and that value equality and diversity can help to improve service quality and meet the diverse needs of disabled customers. An understanding of the barriers that are experienced by disabled people can help to reorientate services so that they address these from an equality perspective. This could include physical barriers in accessing buildings, information and communications barriers, barriers that exist because of an absence of services or gaps in services, or barriers in terms of participation.

Equality of treatment

Equality of treatment by providing services that treat people with respect, courtesy and dignity irrespective of their status or identity. Issues of dignity and respect are important elements of equality in health, social care and social welfare provision. Creating a dynamic process of change and challenging of methods of delivering health services has important implications for the development of equality competent services.

Equality in providing and receiving services

This can be progress by developing and engaging in relationships that are based on trust and care and that promote independence and autonomy for all groups. This also means ensuring that there are no negative stereotypes of assumptions about the culture, status or needs of disabled people.

Equality of participation and representation

Equality of participation and representation requires that disability organisations and people with disability are able to participate in the development of policy making and service delivery, and that they are consulted with in order to gain feedback about service delivery. Giving recognition to the views, experiences and needs of disabled people is a central objective of equality that can be developed through consultation exercises, focus groups, consumer panels, customer feedback sessions, listening sessions etc. An important issue is to ensure that service users are able to effectively feed back on service developments, participate in the planning of services and assist in the monitoring of services.

Equality of outcome

Achieving equality of outcome means identifying the different ways, through mainstream services or through positive action, of providing services so that there is equality of outcome. This means that treating everyone the same will not result in equality, rather services designed for the majority often discriminate against some groups by failing to understand and respond appropriately to their particular needs. Equality means that everyone should have access to mainstream services in equal ways. However, in order to provide equality of outcome it may also be necessary to target services by allocating resources for positive action to address current and past inequalities. This creates the conditions for equality of outcome in mainstream provision. Equality of outcome can also be achieved by ensuring that data properly reflects the experiences of disabled people.

Quality issues in a European context

In conclusion, some of the key elements of good quality services for disabled people can include the following:

• User-orientated services that promote user involvement and empowerment

• Participation of users and staff in quality systems and organisational development

• Quality systems that are flexible, adaptable and relevant to local needs

• Coordinated and integrated service delivery mechanisms that meet needs in multi-faceted ways

• Continuity of services and of funding

• Partnerships of service providers, funding agencies, interest groups, social partners

• A culture of innovation within service organisations that respond flexibly to needs and requirements

• Effective systems of evaluation with feedback mechanisms

• Highly qualified staff who are able to respond to user needs and develop organisational changes to reflect these

• An equality /diversity framework and equal opportunities between women and men to ensure that women's roles as carers or women's care or employment needs are not neglected.

Providers of services should also consider the way in which they can influence the quality of services including:

• More systematic involvement of users, with effective systems of feedback regarding organisational or service changes

• Quality assurance systems developed in consultation

with users and staff that build in proper systems of evaluation and feedback

• Staff participation in organisational development and the management of change through team-working and management structures that allow for organisational flexibility and reflexive, autonomous working environments

• Staff support and supervision and mechanisms to tackle stress, ill-health and burn-out resulting from difficult working situations

• Improving the security of staff working on fixed-term contracts and the long-term sustainability of funding for projects.

What are the principles underpinning quality services?

If we develop a better understanding of the values and principles underpinning service quality and equality what lessons are there for the services for disabled people in Europe? The objective of policy should be to ensure that they operate within a culture of continuous service improvement that stresses efficiency, equality, well-being, social justice and inclusion. Accessibility, flexibility and choice may also be an important component of this as well.

It is here that the fourfold principles of good care developed by Tronto (1993) are helpful; notably of attentiveness, responsibility, competence and responsiveness that can be applied to the ways in which service providers engage with excluded and/or disabled service users. This has implications for the development of training, skills and awareness of staff "...so that the knowledge and experience of disabled people and other service users influences work practices" (Williams, 2001). More far reaching are the implications of a politics of independence and support and voice, championed by the Independent Living Movement, to shift thinking, policy and intervention from a framework of care and support to one of equality, assistance and independence.

2.5. Conclusions

Legal and social policy changes impacting on disabled people include the promotion of the rights of disabled people to full integration and participation in work and society. Best practice includes policy frameworks that combine rights based and public duty based legislation that set out the rights of disabled people to good quality accessible services, equal treatment etc.; and the duties on public authorities to provide quality services, including access to services and information, protections against discrimination and the promotion of equality.

Rapid economic and social changes, a growing emphasis on the social inclusion of disabled people, as well as the social model of disability, raise new questions about what future goals of equality, inclusion, social justice, efficiency and redistribution are needed across Europe to respond to these new opportunities and challenges. In addition, whilst people with disabilities may need mainstream, specialist or targeted medical services, it may be that the medical model is incompatible with the provision of a range of services to support the community integration and equal participation of disabled people in society.

In summary it can be concluded that the following can contribute to good quality services

• User orientated services: involvement, empowerment, equality

• Social inclusion strategies

• Participation of users and staff in quality systems

• Quality systems that are flexible/relevant locally

• Coordinated and integrated services

• Continuity of services and funding

• Partnerships of providers, users, social partners

• Decentralisation of resources and decision making

• Culture of innovation and change

• Effective systems for monitoring and feedback

The role of civil rights and enforceable anti-discrimination laws and policies is part of good practice in evidence in many countries today. This commitment to the promotion of equality and the prevention of discrimination in employment, goods and services, includes in some countries rights to specific services, although in others general principles may underpin equal participation through user-led approaches and a social model of disability.

Computer training

A key aspect of quality is the enhanced role given to users, through user involvement and participation in the planning and monitoring of services and the development of empowerment and independence as guiding principles in service delivery. Whilst accessible and high quality health and social care services are an essential component of good practice, it is important that they operate within a social model of disability and place the user at the centre of the service. A key role for the future of health and social care services is to ensure that there is integration and coordination with the full range of services that are essential for participation in society (health, social care, education, training, transport etc). This also means that services should be provided in a multidisciplinary framework.

Finally, measures to improve the quality of services for people with disabilities needs to consider how barriers to participation can be overcome, how user-led, advocacy and participatory approaches can promote choice and autonomy, how unmet needs can be identified and met, and how quality criteria can be applied to local settings and meaningfully implemented so that the service users experience improved quality and access to services.

These issues raise important questions about the principles that should underpin future developments, the types of indicators, benchmarks or standards that can be drawn up to shape future service developments alongside the ongoing improvements in rights, equality and service development for disabled people. In some cases across Europe reform strategies result from a shift towards more individualised rights and away from mass universal, state-provided and bureaucratically run services, whereas in others, they are a result of emerging state, community, voluntary and private market relationships.

To conclude there are three elements to this process of change in relation to services provided to disabled people. First, the promotion of disability awareness linked to an understanding of social inclusion. Second, the development of user focussed services rooted in the principles of equality, recognition, voice and rights, on the one hand, and of attentiveness, responsibility, competence and responsiveness, on the other hand. Third the development of rights and duty based frameworks.

CHAPTER 3.

QUALITY AND POLICY IN DISABILITY

3.1. Introduction

Why is quality of disability services such a problem? Today users of public services and politicians are demanding higher quality, but why is it so difficult to define more precisely what is meant by that? Perhaps it is because the concept serves a number of different purposes. When users are demanding quality they think of a better assistance, when politicians are putting the same demand they often just want to get the same product at a lower price. Thus a seemingly simple word as "quality" may be of use because it lets everybody believe that they get what they want.

As we know public expenses grew during the 20th century, and disability became one of the leading areas in social care policies. For this reason the organisation of personal social services became an issue. In want of tradition of change and development in these areas, business models of organisation and quality were adopted. Therefore the concept of quality was imported from private business areas in the form of special methods like establishing quality standards (like ISO 9000) or benchmarking, or in the form of general methods comprehending the total organisation like Total Quality Management or Business Process Reengineering (Pollitt, 1997).

In reaction to this development, the professional world has rediscovered their traditional quality methods, peer review and inspection, and given them a much wider application in order to come up to the demands of the quality control that are put today. Unlike business models these professionally based methods have been developed in the area of personal services, which could mean that they are better suited. But such considerations are not the only ones that could be made; the profession-political perspective may be more decisive in practise: business methods rely on the administrative top, whereas professional methods make professionals the central figures.

Even though business thinking was far from traditional public services as well as from social theory, it was sometimes welcomed by social theorists only because it was a way to bring in a long wanted renewal in a rather stagnant area (Evers 1997). The new organisational thinking has opened up for more readiness to listen to the wishes of the users, for giving room for flexibility and free choice, for seeking innovation and bringing more teamwork in. Business models, however, have their drawbacks too. Most often they are designed for controlling the quality in material production where quality is easier to define, or they are using market success as a measure of quality. Defining quality in public services is not quite easy, as reaching the purpose of the production cannot directly be transformed into

action because public service is about human relations, which are politically defined.

Comments on the concept of quality have stressed that it contains a number of conflicts, as each group of stakeholders in an area has its own conception of quality. Administration, citizens, business and professionals have different conceptions of quality (Rajavaara, 1997), as appears from this simplified table:

Group	Aim	Means
Administration	Control, rights	Service standards
Citizens	Participation	User feedback
Business	Market, choice	TQM, ISO9000, benchmarking
Professionals	Peer regulation	Audit, peer review, self-evaluation

Abbreviated from Rajavaara 1997

Certainly quality can be seen as a battlefield between groups with different interests. But for the very same reason, it may alternatively be seen as a means of communication between groups with different perspective and competence. In this project the participating service providers from Portugal, Belgium, Greece and Hungary represent the professional group, and to some degree also the administrative group. The participating research centres from Ausria, Greece and Denmark represent the business, citizens and administration point of view.

Even if this process of quality indicators production does not reflect all the complexity of everyday experience in the services, as the professionals know it, it can nevertheless give the service provi-ders a tool they can use in their development of quality. Quality as a process where points of view from different stakeholders are combined in order to be made use of in the methods development of services is reflected in the quality dimen-sions of the project's conceptual framework: iii. process dimensions of service quality, and iv. impacts for the client.

Both business and professional methods may, however, be rather formal if the purpose of the service is forgotten in favour of measuring. In the 90s the interest has shifted from formal aspects of quality to the outcome of the service in question and from quality control to quality development. But what exactly is the wanted effect of a social service, what is the situation that we consider as need, and in what respects do we want to change it? If we want to evaluate a service to people with disabilities, we have to build on some notion or conception that explains us what disability is about.

With such a basis we can state that the purpose of a service to people with disabilities must be to improve the quality of life. As the next paragraph will show, the concept of disability does not only relate to the level of bodily functions, but as much to the level of social relations. It even has to do with the political role people with disabilities are given, or the role they are taking in society. When talking of people with physical disabilities, quality of life could naturally be defined as equal opportunities compared to people without disabilities. When talking of people with intellectual disabilities, defining the concept "quality of life" is a little more complex.

In a European discussion you cannot help noticing the structural differences in social services, in which the German system with "Wohlfahrtsverbande", the Dutch "regular system" of foundations, the British system where contracting out plays a great role today and the Scandinavian municipal systems are examples. The different structures mean that the situation is characterised by different actors and interests. One may perceive the foreign discussions as irrelevant, or one may understand the situation as a fight between organisational principles - world-view based or charitable principles against commercial contract relations or a principle of public responsibility, in which case there is a tendency to find arguments for one's own system.

A more fruitful use of the structural differences, however, may be to consider Europe an experimental setting for development of social services. The concept of quality may be the tool that makes the experiences in different systems relevant for each other. In this connection the European organisations of disabled people could play a role discussing disability policy and the suitability of structural features.

3.2. The concept of disability

During the second half of the 1900s the concept of disability has developed from the so-called medical model into the relational model, often called the social model of disability (Oliver, 1990; Barnes, 1991; Oliver & Barnes, 1998). The medical model considered disability a defect or a shortcoming of the person, a deficiency or an absence of something that was considered important. It could also be called an essentialist definition of disability.

(The word "disabled" in English in fact sounds essentialist too, combining the root "able" with the negation "dis-", whereas words like "handicap" (=hand in cap) used in Roman languages and Scandinavian, or "Behinderung" used in German talk more about barriers).

The medical model aimed at protecting the group of disabled people against a society where they would be lost. This was done by (a): identifying the persons and (b): isolating them in special insti-tutions, often headed by medical doctors. People with disabilities were made powerless and often given conditions that did not allow for a normal life.

When people with disabilities gained more power

through their organisations, they soon began fighting isolation and tutelage. In connection with this fight for more normal conditions, the new, relational model of disability was developed (Oorshot & Hvinden, 2000). Such a development has probably taken place in all countries where people with disabilities have gained sufficient influence (Bengtsson, 2000). The relational model considers the disabled person a person with the same rights of participation and life as others. Disability is seen as a problem not in the person but in the relation between the person and the physical and social surroundings. It should not be accepted that disabilities result in exclusion; instead forces must be devoted to the removal of barriers in the surroundings in order to provide the disabled person with the same possibilities as others.

Whenever it is possible, problems thus should be solved by making the world accessible for persons with disabilities and by creating solutions that give room for differences, including disabilities. In the relational model of disability, the aim is to neutralise the effects of disability so that the disabled person gets the same possibilities as others, obtains equal conditions and thus achieves real participation in society. This goal is also called equal treatment. During the nineties, equal treatment has become the goal of the European Union as reflected e.g. by the directive of Equal Treatment in Employment and Occupation (Council Directive, 2000/78/EC).

In many cases, however, general accessibility and roominess is not enough in order to obtain equal possibilities for disabled people. It is necessary to supplement this endeavour with provisions that aim at compensating for the drawbacks that follow from a disability in the individual case. This is done by (a): identifying the person and (b): awarding a compensatory benefit that enables the person to take part in activities on equal terms with others. Although such benefits aim at creating participation, they still presuppose that an evaluation is made in the individual case. In this sense the risk of creating dependence of authorities is still there.

Has the relational model then replaced the medical one in European legislation and policy concer-ning disability? The definitions of disability in European national legislation and policy have been surveyed in a recent research project (Definitions ... www). Most European countries today have legislation against discrimination of people with disabilities, and some countries have policies that aim at creating equal treatment by influencing both public authorities and private agents.

This last type of policy is fully in accordance with the relational model of disability. Furthermore, every country has legisla-tion giving special rights to people with disabilities as compensation with the purpose of making them better able to take part in society. This type of legislation and policy is necessary, but it has the disadvantage of presupposing an applying process for benefits and an evaluation in each single case. In such a process the conditions for preserving human dignity are difficult, and dependence is easily created.

To define disability, medical criteria as well as medical doctors" evaluations may be used, in some cases even

so-called "baremes", that is lists of recognised diagnoses. In other cases disability is defined as functional limitations, or as limitation of working ability, through a list of examples ending up with "and other disabilities" (meaning that these explicitly mentioned disabilities are favoured) or just by mentioning the word "disability". The medical model still plays a role for defining disability in the sense of deciding if a person belongs to the group or not. Definitions in the sense of demarcating the group still most often build upon medical diagnoses. Another possibility, which is slightly more in accordance with the relational model, is the use of functional limitation or working capability. But if such criteria when transformed into practice become dependent on medical doctors" judgement, the step away from the medical model is far from great.

The solution mostly in accordance with the social model would be to drop every judgement of a person's disability and demand that society should be roomy enough to integrate everybody in spite of all differences. But even if this were the right direction for a social policy, this step is far too extensive to take today. The relational model does not give much help to sort people into disabled and non-disabled; in fact it involves that such sorting should be avoided as far as possible.

Its contribution to the concept lies in another direction, namely in pointing to the actions that should be taken by society in this connection, and first and foremost to the purpose of disability policy. The purpose is equal treat-ment, which means that people with disabilities have the same conditions and the same possibilities as others, so they can live on the same conditions. If the disabled person - because of intellectual disability - cannot cope on the same conditions as others, the purpose must still be to ensure that equal conditions are present, including freedom of choice and respect for the person, which is necessary for the quality of life.

The social model of disability is important because it stresses that disability is not a question of individual deficiency, but rather a question of policy in the meaning of the authoritative distribution of goods in society (Stone, 1984). The overall development of disability policy has been a shift from a special care model into a model of sector responsibility. Before 1960 the special care model with separate "worlds" for blind, deaf, mentally disabled etc, prevailed in all countries. Since then the new model has been launched, where every sector in society must look after that people with disabilities have access there.

Vehicle repair workshop

tion becomes necessary. This development is similar to the development on other public areas and in private enterprises, as knowledge society replaces industrial society. Whereas the special care model made a bureaucratic organisation natural, the sector responsibility demands public organisation to become more organic.

During the later years the discussion around the social model of disability has, however, become more facetted. Under the heading of "back to impairment" it has been recognised that we have to supplement the social concept of disability with an individual concept (Tomas, 1999). If we want to create something like equal treatment of people with disability, general provisions like accessibility is not enough. They must be supplemented with compensations that are adapted to the concrete individual and situation.

Goffman's analysis of the stigmatisation process (Goffman, 1963) has been interpreted as describing disability as an individual tragedy, and for this reason rejected. The stigmatisation process, however, must not be understood as a necessity, but as a process that may be reversed as Wolfensberger conceived it. This is one component of the individual concept of disability, and its contrast self-confidence, which has been recognised in rehabilitation studies as a most important factor for employment.

Another important element of an individual concept of disability is the concept of functional limitation. It is a natural point of departure for legislation on compensation in order to make it possible for disabled persons to participate in work and daily activities. The experiences that shall give the disabled person more self-confidence can only be created, if compensation for functional limitation is available as a condition for participation.

The project sets inclusion as a goal for the social effort in relation to disability. This excludes the consumer model of this effort, which has been proposed by Albrecht (1999). Inclusion cannot be made a consumer good, but must necessarily involve co-production of services. Furthermore, an effort according to a consumer model would not be to pay. And rising costs is one of the crises of the disability provision system.

There is however a dimension of the individual concept of disability that is seldom recognised. In a Danish study a random sample was asked to define disability (Olsen, 2002). The answers fell in five roughly equally sized groups: one group defined disability using the very word disability, which can in no way be called a proper definition. The second group gave examples such as blind, deaf and wheelchair users. The third group referred to something medical, the fourth to functional limitation. The fifth group accentuated the "otherness" of disabled persons.

The attitudes to disabled persons that were examined in the same study could suggest that this "otherness" should be interpreted as the character of the non-verbal signals which disabled people send out and the predictability of the person. So the "dribbling spastic", the schizophrenic and the mentally disabled were the persons who were most often avoided.

The social model of disability and its use in the project can be illustrated by this table:

Special care model	Forming a world for each disability group	Corresponds to "vi. external structural dimensions" in the conceptual framework of the project
Sector responsibility model	Letting people with disabilities participate in the ordinary world	
Bureaucratic organisation	Following rules	Corresponds to "v. internal structural dimensions" in the conceptual framework of the project
Organic organisation	Pursuing aims	

The individual model of disability can correspondingly be illustrated by this table:

Functional ' limitation	Able to work	Correspond to "ii key aspects: empowerment, quality of life" in the conceptual frame-work of the project
Otherness	Able to participate	
Stigmatisation	Getting a role	Corresponds to "i. inclusion in family, in community, in work" in the conceptual framework of the project
Self-confidence	Taking a role	

The medical model gives a well-defined sorting procedure for deciding who is disabled and who is not but leads to a disability policy of dependence and tutelage. The relational model gives a reasonable basis for a disability policy that deals with the removal of the barriers thus making society roomy and integrating, for disabled as well as for all other groups, but does not provide much assistance in sorting people. It calls for integration and mainstreaming (in Scandinavia often called sector responsibility) and an active role in society for people with disabilities. Furthermore, the relational concept of disability entails that life quality of people with disabilities becomes a public concern.

Is the disability policy part of the social policy? This is often assumed, but disabled people's organisations hold that the needs of people with disabilities should be satisfied in the same way and through the same institutions as for people without disabilities, which is the content of the principle of main-streaming. For many reasons making society roomy, concentrating the efforts on integration, aiming at mainstreaming solutions seem a sensible strategy, not only to solve the

Horse riding school facilities

problems in connection with disability, but also to avoid a number of problems that could arise.

Disability should not become a reason to exclude a group of people from the normal solutions and from the normal agencies of society thus concentrating their affairs in a "social" sector. However, disability policy indeed must be characterised as social policy, if social policy is defined as all sorts of policies that affect the integration or exclusion of groups, and it must contain a number of social benefits, if social benefit is defined as a benefit provided to individuals in accor-dance with a statutory scheme and without any simultaneous contribution of equal worth.

So disability policy is social policy in the meaning of public commit-ment for making society roomier and more faceted. It is not social policy in the sense of creating a special agency that can handle all problems of disability. The logic that binds this paradox together is the social right of participating in society on equal terms. Thus the social rights of people with disabilities and the transformation of these rights into practise by the relevant authorities are central for the realisation of equal treatment of people with disabilities. Thus the quality of the authority exercise is an important quality issue.

3.3. Quality of authority exercise

The first requirement of public authorities in relation to disability policy must be responsibility, not only in theory but also in practise. In every sphere of social life an authority must be responsible for ensuring that what is normally used in our society is accessible for people with disabilities too. The principle of mainstreaming then involves that this authority should be the same as the authority responsible for this function when it concerns people without disabilities. But mainstreaming is only worth the value when this generally responsible sector really takes the responsibility for including people with disabilities as well.

Quite often it is rather difficult to define and enforce a sector responsibility. While public transport was monopolised it was in principle easy to give the monopoly the responsibility for making the means of transport accessible. With liberalisation and competition incitements are created for excluding expensive and troublesome customers and letting someone else take care of them. How can sector responsibility then be combined with the public responsibility for equal treatment of people with disabilities? Such questions must be posed and solved in every case in order to avoid that forms of competition established to increase service quality for the majority does not have the opposite effect for disabled people.

So, the first two requirements to the quality of authority exercise is that there is a responsible authority with an impact in practise, and that the responsibility, as far as possible, is placed in the sector that has the function in question for other people. A third type of requirement that is often put forward in relation to the quality of authority exercise concerns everything that has to do with the formal decision procedure of the authorities. Questions like: has all relevant information been procured, have all parties been heard, how long time has passed with the different stages of the procedure, is the decision substantiated, have the reasons for the decision been communicated to the citizen, has the citizen been informed in a comprehensible way, et cetera.

The quality of authority exercise also involves a number of small procedure issues from the daily functioning. For instance, is it possible to phone the authority and get in touch with the right person, or at least a person who can take a decision, is it possible to get an appointment within a reasonable time, are the users being reasonably well informed about the procedures and about when to expect a decision?

Often the quality of awarding procedures or social casework is understood as merely comprising these formal aspects of consideration and decision, which could be summarised under the heading of "good administration practise". Good administration practise has a double function. It means that administrative work is done reasonable well and thus gives citizens a certain protection against outright power misuse, and for the same reason it protects authorities against accusation. Quality in this formal sense, however, does not necessarily mean that citizens who use public services are happier with them.

Even though formal procedures and good administration practise are important, a satisfactory quality evaluation of authority exercise cannot be reached without dialogue with the citizens affected by the decisions (Schadler, 2002). Good administration is more than good administration practise. Administration cannot be judged on its compliance with formal rules, it is more important that the right decision is reached. And even this is not the most important issue compared to the importance of reaching the purpose of the effort. When solutions to complicated problems such as those connected with disability are made the task of public authorities, laws and rules must also be understood as the means at hand for solving the problems. Solutions must be individualised, as Evers (1995) has put it, the development must go "from taylorizing to tailoring".

If the administration of the disability legislation means that people with disabilities indeed receive the benefits that compensate more or less in accordance with the laws and rules that exist and with the norms of good administration, but we at the same time have created a new sort of disability in the sense that the disabled person has the experience of having to ask permission every time she or he is in need of anything, we have used a lot of resources without obtaining real equal treatment.

A true dialogue with the citizen that ensures that the purpose with legislation is obtained is therefore a necessary part of the quality of authority exercise. A dialogue principle has begun to appear in social legislation, but, in the nature of the case, it is not easily put into practise without comprehensive work. The white papers of the Bengt Lindqvist commission in Sweden are a remarkable contribution to this work, which in the following years has to include social research as a most important part (Lindqvist, 1999). The concept of dialogue between citizens and authorities that they are using is not simple, and it can only be managed if understood much better.

The more personal social services for people with disabilities are in accordance with the relational or social model of disability, the more they have to be split up into parts in order to design the total effort attuned to the individual need. With individual solutions follows a role as counsellor in composing such a service "packet", the role as care manager. This figure has been part of the Scandinavian systems of social service since the seventies or eighties, and here the case manager fulfils a double function: at the same time she is the person that informs and gives advice to the citizen who addresses the authorities to get the help they are entitled to, and the person that, as a representative of the social authorities, decides what shall be yielded. In this system individua-lisation of the service has the paradoxical effect of multiplying the number of situations where authori-ties take decisions of vital importance for the citizen. In this section we shall consider the caseworker role as a decision maker, whereas the role as service designer shall be considered in the next section.

With a caseworker role perceived as a decision maker bordering on life administrator for the disabled person, methods to create a relation of mutual trust and respect between citizen and caseworker is central for the good functioning of the system. The first results of an ongoing project show signifi-cant differences in service quality from caseworker to caseworker according to citizens' assessments, whereas differences from authority to authority are much smaller and not significant (Bengtsson, 2003). If we distinguish between the organisational factor and the personal factor, the latter seems the more important.

Rehabilitation through hipotherapy

3.4. The concepts of personal social service and care

Public provisions in relation to disability can take the form of cash payments or of social services. The two nouns "service" and "care" cover the same activity, but with the weight put differently. Service means something that serves the user, who is the person in power in this connection. Care is also for the person's sake, but the weight is somehow attached to the caregiver who is thought of as having a special knowledge or as contributing emotionally with a special carefulness. None of these words are quite simple, however:

Care may be:

• dependent on a special professional knowledge or on a person making professional judgement;

• dependent on understanding and human emotion, and the feminine element may be stressed (Ness & W?mess, 1997);

• or it may be seen as a caricature of these two stressing tutelage and dependence on professional power (Lipsky, 1980).

Social service may be seen as something that is produced and made available for certain persons. But what kind of "thing" is it?

-1- it can be conceived just like any *material product*, which means that it is possible to use the same quality methods as in private material production.

-2- or, in the conception the weight can be attached *to the quality of service*, in which service is defined as a sort of commodity that is produced and consumed in the same process. This entails that the user is part of the product and that the product must be understood as a relational phenomenon. It also entails that the producer is part of the product. The service producer should have a considerable freedom, and the service giver should be acceptable to the user (Bengtsson 1997).

-3- or, the weight can be attached *to the social quality*,

the quality of being a public responsibility: social service is not for sale in a market, but made available for a certain group in accordance with the authorities. Even if user ticket may occur, most of the cost is subsidized.

To determine the concept of social service we shall use the two components of this expression, "social" and "service", one by one.

By "social" we mean that the service is part of the social protection system, a public provision which has been created to solve some of the problems that are caused by disability. A social service is financed wholly or partly by a wider community, which may be the state, the municipality, or some statutory arrangement.

A social provision that is purely distributive takes the form of a cash transfer. The person who receives such a benefit can use it as she or he wants. When a social service is provided, the reason is that the wider community not only will modify the distribution of goods, but also wants to decide for which purpose this benefit is used. We often say that social services are there to fulfil "needs". This is not, however, to be understood as they are defined by the receiver, but as they are defined by the agency that pays for the benefit.

So there must be a certain amount of control that the services that are offered in fact are the services which should be provided. At the same time, such a control should respect the person who receives the services.

By "service" we mean a commodity that is produced and consumed in the same process. This means that the service producer cannot be separated from the service that is produced, but must be seen as part of the product. The personal qualities of the service producer is thus an important part of the service product.

The service receiver is a part of the product, too, as social services in most cases presupposes that the receiver takes part in the production as a co-producer. So, a social service can be illustrated by the following scheme:

> **Social** = we do not give you what you think you
> need or what you say you want,
> But what we have decided you shall have
>
> **Service** = product that is produced and
> consumed in the same process
> This makes both producer and receiver
> parts of the product

These implications of the concepts "social" and "service" get as consequence that the goal displacement, which is a common phenomenon in organisations, in the organisation that provides social services to people with disability is supplemented with a process of power displacement.

The goal is to make it possible for the disabled person to live a life as near to the life of other persons as possible. But if the provider of services is also the controller, this goal is very easily displaced. Furthermore, as the product can only be produced in cooperation, and the service receiver is more dependent on it than the

producer, there easily comes a power displacement as well. There is a danger that disempowerment rather than empowerment becomes the outcome of the service (Bengtsson, 2003).

3.5. Quality methods for personal social services

Business quality methods were introduced when public expenses were being controlled and if possible reduced, and professional quality methods can more or less be understood as disabled people's defence against business methods. Increasing the quality to the benefit of the citizen using the social services has been a justification rather than a real purpose of these endeavours. If quality is defined as certain formal criteria, quality control becomes a way to limit expenses without any guarantee that more than formalities are produced. So it should not surprise anybody that we often find that the use of these quality methods does not add to the quality as experienced by the user, but on the contrary reduces it.

When considering the professional quality methods, we see that, related to professional knowledge, only the first aspect of care is grasped. They cannot, or will hardly, evaluate the understanding and emotional element in care or the asymmetry of professional power and the suppression of clients. Likewise, business methods only catch the first mentioned aspect of social service. The service quality means that the citizen using the social services must have a place that is not reflected in business methods, and user evaluations must be of central importance. It also means that the service giver must have a much more spon-taneous role than these methods provide for. The social quality of social service means a difference between user and customer, contrary to what business methods are supposing.

As mentioned, the interest has shifted from formal aspects of quality to the outcome of the service in question and from quality control to quality development. Continuous evaluation and improve-ment of care quality is emphasised, and the interest is focused on the effect that the service has on the client (Schalock, 1996). These critics mean that the point of departure in defining quality of services must be the result, considered in relation to the intention with the service. Of course this outcome must be related to the costs in order to ascertain efficiency of the effort. The services must make a difference to the people with disabilities that is in a reasonable proportion to the cost, and they must result in a better quality of life. This brings us to the next problem, the problem of defining the concept "quality of life".

With a relational concept of disability, the disabled person must have the same possibilities to participate in society as others. If the disability is a physical disability, the person does not need any special understanding, emotion or tutelage, but a professional knowledge is often important. This knowledge must, however, be put to the disposal of the disabled person. So the concepts of social service are the most appropriate. If the disability is a learning disability, the person cannot par-

ticipate in society on the same terms as others.

Even if the old principle of "normalisa-tion" in the meaning of Bank Mikkelsen (1999), the creation of surroundings providing, as much as possible, the conditions needed for a life like other people, could be a guide for the effort, the situation of people with a learning disability is very different from the situation of people with a physical disability. For physical disabled people life quality could be identified as "equal opportunities". For intellectually disabled people a more substantial definition of quality of life is necessary. In both cases, however, the challenge consists in finding ways to liberate people from the social services, so they can naturally (but often with significant support) make use of general community resources and opportunities.

In order to relate our indicators of quality standards to disability theory, I define a simple model of reality, consisting of two elements: user and provider of service. I shall consider each of these, and the relation between user and provider. The following three schemes illustrate the relation between these concepts and the dimensions of service quality we have set up:

User

Self-confidence	Taking a role	
Stigmatisation	Getting a role	i. Inclusion in Family Community Work
Functional limitation	Able to work	
Otherness	Able to participate	ii. Key aspects Empowerment Quality of life

Self-confidence represents the universal concept of social actor, a role which is fundamental for all human beings, but not as obvious for people with disabilities as for the rest of us. Stigmatisation stands for the result of a possible mechanism, which may but need not be there. National differences are considerable. Functional limitation is a common way to define disability, when one wants to find an alternative to the medical model. But it does not exhaust all of the reality in disablement. Studies of attitudes to disabled people have revealed that the concept of "otherness" is relevant too. Qualities by interaction and communication, in the signal systems between people with verbal and nonverbal means, operate so as to reduce the forces of integration at their very foundation, and thus widen the distance between the disabled person and the non-disabled.

All these concepts are leading to our first two dimensions of indicators, to the first of them through the concepts of role, and to the second of them through the concept of ability.

Instead of provider, I use the more Scandinavian term

of "system". In our case the social services are so institutionalised that we often use the term system, which denotes that services are not just some help in a situation, but also an authority you have to adapt to.

System

Bureaucratic	Following rules	v. Internal structural dimensions
Organic	Pursuing aims	
Special care	Form a world	vi. External structural dimensions
Sector responsibility	Participate in the world	

System is also a good word because it stresses that service provision is always taking place through an organisation, even if it sometimes tries to hide itself behind the image of the good Samaritan. An organisation has to be more or less bureaucratic. Without forms and rules, it is not at all an organi-sa-tion and cannot be used for any purpose. But just following rules is not an effective way to get things done. The bureaucratic structure must be supplemented with organic features in order to over--come the forces of bureaucracy, which create ritualism, and the forces of profession-gover-nance, with mixing of professionals" narrow interests with the goal of the organisation.

The system that addresses itself to integration of people with disabilities can make this integration in two widely different ways. They may build up a world around the disabled person that is adapted to the disability, according to the principle of special care. Or they may try to adapt the ordinary world to the disabled person, according to the principle of mainstreaming, or sector responsibility as we call it in Scandinavia. The last alternative is the most promising for the disabled person, and the first one should only be used when mainstreaming is not possible.

A power balance, a balance between the power of professionals, the power of users, and the power of bureaucracies may be more dynamic than a power-free relationship. The last two dimensions of service quality concern the relation user-system:

User-System

iii. Process dimensions of service quality: Access, choice, influence, trust, safety, service responsiveness, service integration, universal right
iv. Impacts for the client: Client-service relation specified for each stage: pre-entry, entry, needs assessment, service planning, delivery, exit

3.6. Conclusion

It should be clear now that the quality of an effort to support people with disabilities depends on many things. Legislation on rights and provisions, provider organisations in the public and the private sector, and economic means play an important role. But political consciousness, the organisations of people with disabilities, and the concept of disability as it is conceived by authorities, providers, disabled people and the population in general, are important too in relation to the question if provision of services will meet the needs of people with disabilities.

What is a need? It is often conceived as a more-or-less fact. In reality needs are very far from being facts. An example can illustrate this. In connection with establishment of a centre for walking aids and other aids for disabled people in Latvia in the late nineties, the need of such things should be evaluated. This was done in two ways. First, the Latvian budget for this was compared with the budgets of Sweden, Norway and Denmark. So considered, the Latvian budget made up 2% of that in the other Scandi-navian countries.

The need could however also be evaluated in a quite different way. Most municipalities had got a lot of wheelchairs and other equipment from friendship cities and organisations in the west. Some of them had got so much that they has surplus of all things. If we tried to calculate how much it would cost to maintain a stock of that size for the entire country, the Latvian disability aids budget turned out to be quite sensible.

This and many other examples show that social development is as much creation of needs and expectations as it is fulfilment of known needs. A need cannot be seen as a fact by the needy person, but should rather be understood as a property by the person's environment, and by the society where the person lives. Need is determined by what most people want to be done for the person, and by what the society is able to do for the person. Perhaps it could be expressed as follows: need is always 5% more than we have!

People with unfulfilled needs, and needs they can never fulfil, feel powerless. When these people are assisted in society, it is important if most people consider this powerlessness as acceptable or as not acceptable. It is also important if it is a situation where most people expect to come, or have a considerable risk to come, or a more special situation. According to this we get four types of social services:

Types of Social Services

	Powerlessness is accepted	Powerlessness is the problem
Normal situation	child care, elderly care	activation, vocational rehabilitation
Special situation	services for disabled people	family problems, homelessness

In the field with "services for disabled people" we could also place "employment for disabled people", in so far as some degree of powerlessness is accepted, and the demands on this labour force are often less than the demand on others.

Need is not the same as want. Social services aim at fulfilling needs, but they do not give people what they want. This is the reason why we cannot just give the clients money instead of services. There is a paradox: we want empowerment of the client, but is it possible to empower when we decide what the user shall be offered? The answer must be responsiveness by the service provider.

There is a paradox of normalisation too. Normalisation means according to Bank-Mikkelsen to make a life like other peoples" possible. In order to make that, a number of services are established that aim at integrating people with disabilities. But it is not normal to use disability services. And they may be an important element in the user's life. Thus, in order to create normal conditions, we have introduced something that separates the disabled person from the normal.

It is therefore important to ascertain that the services, and the awarding procedures that may lead to the services, do not create new barriers for the disabled person, and do not represent new burdens that are laid on their shoulders instead of those, which the servi-ces were made to remove. This matter will cause a number of concrete problems in any service.

Quality standards have a number of functions. This is about functions in the provider organisation as well as functions for the user. They may furthermore get a function in the political process of defining the social rights of disabled people.

In the provider organisation quality standards have the following functions: they contribute to defining the service provider organisation;

• they make the provider organisation more goal-oriented;

• they strengthen provider organisation in relation to the user.

The last mentioned function entails a danger of provider dominance.

Quality standards have the following functions for the user: as quality standards strengthen the service provider, the user begins to act strategic;

• this threatens the trust between provider and user.

The latter point makes it necessary that an effective and empowering feedback mecha-nism is creating the needed responsiveness

From all of the points mentioned in the foregoing it emerges that responsiveness is the focal point, and the general quality by a disability service without which all other demands are meaningless. The client who is listened to will contribute more to solving the problems. The client who isn't listened to will make demands and expect the provider to solve the problems.

Part II: THE PROJECT APPROACH TO SERVICE QUALITY

PROJECT FOCUS AND CONCEPTS

4.1 The policy context

The starting point for this project and its partners was concern with groups of people who are poor, marginalized or suffer from handicaps and are vulnerable to the risk of social exclusion; and in particular people with disabilities. These groups have multiple needs that demand coordination and an integrated response from public services, and an approach that responds not only to their material or health needs but also to their psychological and social needs.

Public social services represent a vital factor for combating the risk of exclusion and enhancing the quality of life of these groups and also for strengthening social cohesion. This, and the fact that people with disabilities and their families are dependent on public social services in order to be able to cope with daily life, makes the quality of service provision a key issue in relation to inclusion.

The relevance of public social services for the inclusion of vulnerable groups has become in the last few years an important social policy element in Europe. This is reflected in the Community initiative to introduce in 2001 the National Action Plans for Inclusion and in 2004 the Joint Action Memoranda for the new member states of the European Union. Key aspects of service provision, such as service accessibility, client empowerment, service integration, are increasingly recognized as being critical preconditions of service quality and have become part of quality improvement initiatives in most member states.

The project covered four types of disabilities and respective services: mental health problems in Greece and Slovenia; mental and motor disabilities in Portugal; physical disabilities in Belgium; sensorial disabilities in Hungary. The task of the project was to define service quality and quality indicators and to develop and pilot quality assessment tools, in a way that would incorporate key aspects of service provision such as the above and reflect the perspectives of the different stakeholders involved, especially the perspective of service clients.

The objective of the project was to develop tested service quality assessment tools that would be applicable to broader range or disabilities and services, beyond those covered by the project and its partners; facilitate the sharing of experiences and the identification of good practices among service providers within the same service or across services; and offer inputs for incorporating service quality objectives and measures into social inclusion policies.

4.2 The project partnership and its objectives

The project partnership brought together two types of partners. It included:

• Organizations with research and policy competence in the fields of social policy, exclusion and disability, from three countries: PRISMA - Centre for Development Studies in Greece; the European Centre for Social Welfare Policy and Research in Austria; and the Danish National Institute of Social Research in Denmark.

• Service provider organizations catering for different client groups and types of disability from five countries: the Society of Social Psychiatry and Mental Health (SSPMH) in Greece; the Portuguese Association of Cerebral Palsy - Central Region Nucleus (NRC-APPC) in Portugal; the National Association for the Housing of Handicapped Persons (ANLH) in Belgium; the Association of Nonprofit human services, the Social Innovation Foundation, and the Foundation for Helping Disabled People - MOTIVACIO in Hungary; and PARADOCS in Slovenia.

Service provider partners contributed to the project their service-specific experience and commitment to service quality; and provided a real-life test bed for the pilot application of the service quality assessment tools developed by the partnership. They have used the pilot application to assess the quality of their own services and initiate improvements; they have made it available to their service provider community in their country; and offered relevant inputs to the national policy making process.

The project spanned a three-year period (2003-2005) in two phases.

In the first phase (2003), existing research and policy lit-

erature on disabilities and service quality was studied; service providers among the project partners reviewed their service practices and approach to service quality; and the partnership developed a conceptual framework for approaching the assessment of service quality. The framework brought together partner experience and approaches to service quality and was built at a higher, "generic", level so as to be applicable not just to the specific disability services included in the project, but more broadly to social public services addressed to vulnerable groups which are dependent on these services.

In the second phase (2004-2005), the partnership was enlarged with the participation of another three countries and four more partners, including an additional service provider partner in Hungary; service quality assessment tools were designed for each of the four service provider partners in the project on the basis of the conceptual framework produced in the first phase; and these were then piloted by service provider partners. This Guide is the result of these four pilot applications of the quality assessment tools and incorporates the lessons learned by the pilot application.

4.3. The project concepts and approach to service quality

The project adopts a specific view of service quality and approach for the assessment of quality and the formulation of quality indicators. This view takes the service client as its focal point; acknowledges that clients have multiple needs that require complementary services from a range of organisations and professions; and construes service quality accordingly.

This view departs from the so called medical or professional model which defines disability as a problem at the individual level and equates it to a functional limitation or defect of the body or mind whose treatment is determined by medical knowledge and practice only. Instead it incorporates into the definition of disability the relational or social model that treats disability not merely as an inherent attribute of the individual, but as a product of the person's environment and social context.

This definition of disability and view of service quality leads to the construing of service quality - to a model of service quality - as a hierarchy of concepts:

• Client inclusion, regarding family, community and work, as the ultimate mission of service provision.

• Empowerment and quality of life of the client, as the end objectives of service provision that can make inclusion possible.

• Core dimensions of service quality, such as access, choice, participation, trust, safety, responsiveness, service integra-
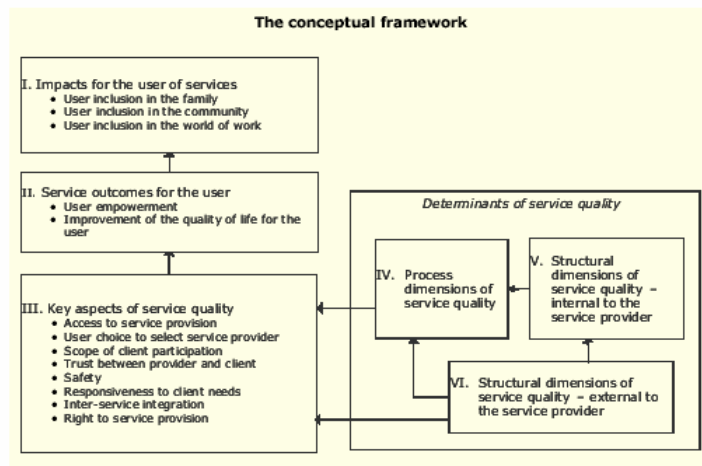

Employment advice office

tion, right to service, as key preconditions for the empowerment and quality of life of the client.

• Process dimensions of service quality, which reflect aspects of the relation between service provider and client and service co-production throughout the cycle of service provision.

• Internal determinants of service quality, which reflect aspects of service provider structure and resources that affect the quality of service provision.

• External determinants of service quality, which reflect aspects of the environment outside the control of the service provider that affect directly or indirectly the quality of service provision.

This model of service quality represents a generic framework for treating quality in a holistic way and designing quality indicators and assessment tools that would be applicable to a broad range of social public services, well beyond the particular types of disability services covered by the project.

The conceptual framework

I. Impacts for the user of services
- User inclusion in the family
- User inclusion in the community
- User inclusion in the world of work

II. Service outcomes for the user
- User empowerment
- Improvement of the quality of life for the user

III. Key aspects of service quality
- Access to service provision
- User choice to select service provider
- Scope of client participation
- Trust between provider and client
- Safety
- Responsiveness to client needs
- Inter-service integration
- Right to service provision

Determinants of service quality

IV. Process dimensions of service quality

V. Structural dimensions of service quality – internal to the service provider

VI. Structural dimensions of service quality – external to the service provider

CHAPTER 5.

THE PILOT APPLICATION OF THE QUALITY ASSESSMENT TOOLS

5.1. The field and method of the pilot application

The assessment tools developed by the project partnership were tested in four different countries and service provision settings by the service provider organisations of the partnership. They represent four different groups of people with disabilities covered by the project: people with mental health problems in Greece, cerebral palsy sufferers in Portugal; physically disabled people in Belgium, people with sensorial disabilities in Hungary.

The pilot application was managed in each of the four cases with a small work group with no more than 3-4 members. They included one or more members of staff and a senior manager, drawn form the service provider organisation and an outsider, drawn from one of the research/policy organisations of the partnership, who acted as an independent advisor for the rest of the group.

Vocational training in cattle farming

Notably, clients were not represented in the management of the pilot appliocation. The effect of their absence was somewhat mitigated by the particular circumstances and profile of the provider organisations. In all four cases, client empowerment was in itself a central element of the mission of the service provider and its service provision practice; whilst, at least in two of the four cases, the service was set-up by the clients and the head of the service was a former client himself.

The pilot application was organised in five steps. In Step 1, the field for the service quality assessment, i.e. the service setting and the client group to be covered by the assessment, was chosen.

● In Greece, the setting of the pilot application conducted by SSPMH was the Institute for Child and Adult Mental Health, a not-for-profit organization located in central Athens closely associated with the SSPMH. The Institute provides out-patient psychiatric and psychotherapeutic services to people with mental health problems and to their families, at its premises or at home, and promotes de-institutionalization of mental health patients and the amelioration of the risk of social exclusion for people with mental health problems. The Institute's professional approach follows the psychodynamic model and the principles and philosophy of social psychiatry. It has a staff complement of 30 professionals. The pilot application focused on the Institute's services for adults and two groups of respondents took part in the survey: clients and staff.

● In Hungary, the service setting of the pilot application conducted by ANHSH and SIF was one of ANHSH members, the MOTIVACIO Foundation for Helping Disabled People, an NGO set-up in 1996, located in central Budapest. The pilot application focused on the services offered by the Employment department of MOTIVACIO to people with sensorial disabilities (blindness and deafness). The department offers a very wide variety of services to unemployed people such as consultation, labour advice, planning, career advisory service, job-hunting advice, and psychological consultation and works closely with employers.

● In Belgium the setting of the pilot application, conducted by ANLH were three ADL (Assistance in Daily Life Service) services; one in Brussels and two in Flanders. ADL services include residential accommodation in special-purpose apartments for people with physical handicaps and offer a 24-hour, 7-days a week, service to the residents. ANLH is an association of disabled and able-bodied persons set-up more than 30 years ago with a mission to further the social integration of people with severe physical disabilities by providing housing and an environment adapted to their needs, personal assistance services, and promoting accessibility for the physically disabled through research, training and campaigning.

● In Portugal, NRC-APPC used its own services, which include a Rehabilitation Centre and a Farm in Coimbra, as the setting for the conduct of the pilot application. The application focused on people with cerebral palsy condition, who represent its main group of clients. They suffer from learning disabilities, mental handicaps and behavioural disturbances, motor disabilities, or a combination of those, as a result of their cerebral palsy condition. NRC-APPC is part of the national Association for Cerebral Palsy. It was founded in 1987 by a group of

parents whose children suffered from cerebral palsy, and from its base in Coimbra covers the whole of the central region of the country through its mobile services. It provides a full range of services to cerebral palsy sufferers and to their families, including rehabilitation, schooling and professional training, occupational activities, residential accommodation and domiciliary services, counselling, and labour market placement.

Once the service setting and the client group for the conduct of the pilot application were chosen in Step 1, the next four steps followed:

• In Step 2, a preliminary assessment of the quality of the service in the setting chosen was conducted. Each service provider went first through all the items of the conceptual framework and identified those items that were relevant to its service. Then for each item that was considered relevant for its service a factual description of the service was prepared ; problems and areas of improvement with respect to the quality of the service were identified; and the data required for the assessment and its sources - i.e. interviews and survey data with the different groups of actors related to the service, statistical data, and documentary data - were determined.

• In Step 3, two or more survey questionnaires were designed by each service provider, depending on the number of the different groups of actors related to its service.

• In Step 4, the survey questionnaires were administered to the groups of actors related to the service and their responses were analysed. The findings of the surveys, together with the conclusions of the preliminary assessment and additional statistical or documentary data collected, were merged into a quality assessment results report.

• In Step 5, the results of the quality assessment were reported back to the staff, the clients, and other groups involved; discussed and interpreted; and acted upon by the service providers - a process which at the time this report is being written is continuing.

The survey of staff and clients -and in the case of MOTI-VACIO of employers and service donors- represented the core element of the assessment. It was essential for tapping in a systematic way the perspective of the different stakeholders involved, especially those of the clients of the services.

The design and content of the survey questionnaires were based on the conceptual framework of the project developed during the first phase of the project. The framework offered a generic, common, service quality agenda that was adapted to the circumstances of each service being assessed.

The following three sets of data were covered by the survey questionnaires for each group of respondents:

• Data concerning the socio-economic - and where relevant the professional - profile of the respondents.

• Data concerning the views, perceptions and experiences of the respondents - service clients and staff as well as of other actors where relevant -, regarding the whole of the service provision process, i.e. the initial

contact between the client and the provider organisation, the assessment of the needs of the client and the preparation of the serviced plan, the delivery of the service, and exit of the client from the service. In this set of data, the same questions were asked from the clients and the staff, where appropriate, in order for their respective views to be comparable.

• Data concerning the views, perceptions and experiences of the service staff regarding a range of aspects affecting service quality such as: the adequacy of staff resources in relation to service needs; the service facilities, commitment to the service mission; relations with colleagues; the climate of work; personal development and training needs; job satisfaction; participation.

The survey questionnaires were adapted to the particular conditions of each service provider setting and respective respondent groups. The following respondent groups were covered:

• In the case of SSPMH: clients, staff.

• In the case of ANLH: clients, supervisory staff, assistant staff.

• In the case of MOTIVACIO: clients, staff, employers, service funding sponsors.

• In the case of NRC-APPC: clients, client families representing clients who did not have the capacity to respond to a questionnaire because of their cerebral palsy condition, staff.

Two different methods were used for the completion of the questionnaires: personal interviews and self-completion. In both cases questionnaires were anonymous and particular care was taken to preserve the anonymity of staff respondents by avoiding any questions through which their identity could be revealed. Personal interviews were used for clients and staff in the case of ANLH and for clients in the case of MOTIVA-CIO. In both cases the use of personal interviews for the clients was dictated by their disability condition, which made self-completion very difficult. In the other two cases questionnaires were completed by the respondents in private and were returned in an anonymous sealed envelope to a member of staff or dropped - completed or blank- into a ballot box.

Response rates varied from just under 50% for clients and staff in the case of SSPMH, to between 60-70% for the NRC -APPC case, to over 80% in the case of ANLH and MOTIVACIO. Where the method of personal interview was used, as in the cases of ANLH and MOTIVACIO, response rates were higher as could be expected.

5.2. The results of the pilot application

The full reports of the pilot application for each of the four cases, the results of the assessment and the way these results are being valorised, are available in the website of the project www.quality-disability.net.

Overall, in all four cases, the findings of the assessment were found to be quite positive in most respects, regarding the quality of the services offered, especially concerning the staff-client relations throughout the process of service provision: from the stage of initial contact and client entry to the service, to the stage of

Iconography workshop

the assessment of client needs and planning the service, and the stage of service delivery. Notably, in most respects, there was consensus between clients and staff about the quality of the services provided, with the staff being consistently slightly more reserved than the clients in their positive assessment views.

At the same time, a range of shortcomings were identified -or confirmed in some cases- and the staff and clients made suggestions for improvement; and in all four cases there was action follow-up of the results of the pilot application.

The assessment of the service provision process
Provider choice and service entry stage

Service quality in the initial contact of the client with the service was assessed by the clients by asking them: to state how they learned about the service provider and whether they considered alternatives; to judge their interaction with staff of the service provider in terms of being able to find the person responsible with ease, being treated with courtesy and respect, being given enough time to state their problem, being given adequate answers; and to state whether they had to wait long for the first appointment.

Client responses about the quality of interaction with the staff, at the initial contact stage, were positive in proportions around 90%; but there was concern in some cases about the absence of written information setting out clearly the service conditions and about delays in arranging the first appointment with the staff. The staff shared in some cases client concerns with lack of written information and delays in arranging the first appointment. In some cases the staff were also concerned about the quality of the brief prepared by the service reception; they identified shortcomings in the brief concerning the socio-economic profile of the client and lack of social work resources for this stage.

The scope for client choice between alternative service providers differed substantially among the four cases. This could be expected, given the differences in the type of client disability involved and respective type of service involved. Only in the case of SSPMH there was substantial scope of choice, with almost 70% of the clients having considered alternative providers before

coming to SSPMH. In the other three cases, a small proportion of the clients had considered alternatives; especially in the cases of ANLH and NRC-APPC as in their case they were practically the only service providers with the technical facilities needed for the type of disabilities involved.

Needs assessment and service planning stage

Clients were asked to evaluate the experience of their diagnostic appointments with the service provider staff, during which their needs were assessed and the service plan was prepared. Clients were asked to judge the quality of their interaction with the service staff in this stage with a set of questions similar to those used for judging their first contact with the service, i.e. if they were treated with courtesy and respect, if they were able to express themselves, if they were given enough time to explain their case, if they were given adequate answers to their questions, etc. In addition, they were asked to comment on their service plan, i.e. whether it was consistent with their expectations and responded to their needs; whether they were involved in its preparation and had the opportunity to discuss it; and whether their consent was asked.

Overall, client responses were very positive about the quality of their interaction with the staff, in proportions over 80%. In all four cases, client responses were less positive regarding the service plan itself, their understanding of it, their involvement in its preparation, and being asked for their consent.

Staff responses to a set of similar questions regarding the assessment of client needs and the preparation of the service plan, were less positive that those of the clients, especially concerning client understanding of the service plan and their involvement in its preparation.

An issue that was especially raised in one of the four cases, that of SSPMH, involved the question of having a written contract between the client and the service, that would specify the service plan, the conditions of service and the obligations and rights of each side. In this case the majority of the staff rejected this and objected to putting this question to clients in the first place.

Service delivery stage

Clients were asked to describe and evaluate a variety of aspects concerning their service experience, such as the involvement of their family; aspects of their interaction with the staff; the delivery and effect of the service; practical aspects of the service provided, the involvement of complementary services, etc.

Overall, client responses were positive in proportions over 70% regarding the quality of their interaction with the service staff during the service delivery stage and aspects such as being able to understand better their condition; having their expectations fulfilled and experiencing progress in their condition; being able to discuss changes in their condition and service progress with the staff; and with service facilities, except in one or two cases.

Adapted house

Staff responses regarding the service delivery stage were consistent with client responses, although in many respects slightly less so. There were cases where the staff were particularly critical of the relations with complementary services or other institutions whose involvement had a bearing on the service.

Client exit stage

Like the issue of client choice of service provider, the issue of client exit was relevant mostly, if not only, in the case of SSPMH. In this case, the issue concerns mental health clients who decide to dropout of the service against the opinion of their therapist before their treatment is completed and obviously reflects on the quality of the service. In the case of SSPMH the dropout rate was around 40%, which is in line with international standards for mental health services of the kind offered by SSPMH.

It should be noted that former clients were not included in the survey in all four cases. In the case of SSPMH, current clients were asked whether during their therapy they had any doubts about continuing their therapy, whether they considered discontinuing therapy and in that case what were the reasons. Interestingly, slightly over half of the Institute clients stated that they did consider discontinuing their therapy at some time in the past.

The assessment of the service structure

Aspects concerning the profile and quality of staff resources were found to be important determinants of service quality. They include a range of aspects such as: the adequacy of staff resources; internal staff consultation; commitment to service mission; work climate; terms and conditions of work; job satisfaction; personal development and training opportunities. Staff views on these aspects differed across the four cases and across this range of aspects

Internal staff consultation was identified as a central issue throughout the service process in all four cases. In all four cases staff reported that they were able to get advice when needed but at the same time they stated in greater or lesser proportions that they needed more.

In the case of SSPMH, staff consultation involved regular weekly staff meetings and client case conferences, especially for incoming clients, as standard practice; as well as staff appointments with a senior consultant outside the service. Nevertheless, staff reported a need for more consultation support. In the case of MOTIVACIO, case conferences were also standard practice but the staff also reported a need for more consultation. In the case of NRC-APPC, staff consultation was built in the service organisation; the staff was organised in multi-disciplinary teams that followed the client throughout service delivery process starting from the first appointment for the assessment of needs and service plan preparation. In the case of ANLH, the nature of the service did not call for staff consultation as much as in the other three cases, but the need was present and staff reported it as important.

The adequacy of staff resources was assessed by asking the staff whether the existing staff met the service needs, regarding staff qualifications and experience as well as their number by professional and administrative staff category. In all cases, except in the case of ANLH, current staff was considered as adequately qualified for their function in the service, but at the same time the staff reported shortages that were quite acute for some professional categories.

Commitment to a service mission was an important aspect shared by all four service provider organisations. This was strongest in the case of SSPMH and MOTIVACIO whose staff felt that it was shared by the staff and applied to everyday practice in proportions over 80%. It was less strong in the case of ANLH and NRC-APPC.

The staff, in each of the four organisations, was asked to assess their professional and work relation with the service provider, regarding staff participation, and a range of job satisfaction aspects. They were asked to what extent they participate in decisions concerning the organization of the service provider, the way it operates and the development of service provision practices. Overall positive responses were around the 50% mark.

The staff were asked to assess their job satisfaction in relation to a range of professional and work-related aspects, such as, professional work content, professional development opportunities, training opportunities offered, the climate of work with colleagues, and employment conditions. In all four cases, the staff reported high levels of satisfaction in proportions between 60-80%. In contrast, in all cases, except in the case of NRC-APPC, the staff reported not being satisfied with the terms and conditions of work. In all four cases, the staff stated the need for more training. This was particularly marked in the case of ANLH assistants who lack any professional training.

Follow-up

In all four service provider organizations there was follow-up of the assessment results. All four service providers have decided to expand service quality assessment in other parts of the service and/or to replicate the survey of staff in clients every 2-3 years. In all four cases, reporting back assessment results and dis-

cussing these with the staff has led to changes. A typical example is the case of SSPMH, where the staff that led the assessment reports an increase in the engagement of the therapists group, the enhancement of the training and advisory support for the staff, the streamlining of the client intake process, and the strengthening of the case conference work. Parallel to these developments, the method and tools developed are now being adapted by SSPMH for the assessment of service quality at the Children's Department of the Institute which was not covered by the pilot application

5.3. Lessons learned: methodological implications

Out of the experience of the project as a whole and of the conduct and results of the pilot application, a number of lessons have emerged concerning appropriate methods for designing and organizing the assessment of service quality in a social public service, at the level of the service provider. These lessons have been brought together in the form of a Service Quality Assessment Guide, which is available through the project website. Here these lessons are summarized in the ten key guidelines that follow:

1. Choose the service setting to be assessed

Many service organisations provide a range of services addressed to clients with different needs and profile. In these circumstances, a choice has to be made as to which part or parts of the service and its clientele the quality assessment should cover, or whether it should cover the whole of the service.

The choice should depend on the size of the organisation; the range of different types of client and services offered; prevailing values about service quality within the provider organisation; likely attitudes towards service quality assessment among staff and clients; and the end objectives of the actor or actors who take the initiative for the assessment. In the case of large organisations without prior experience of quality assessment it is advisable to make a start from a part of the service and proceed gradually.

2. Identify the relevant actors

Groups that are involved directly in the provision of the service, as service providers or recipients, and therefore have a direct interest in the quality of the service, as well as other groups or bodies that are indirectly involved should be identified from the start. At a minimum, these groups will include the staff of the service and its clients, and where appropriate the client families or relatives.

Other groups with a legitimate interest in the quality of the service may include public actors with regulatory, funding or policy making roles affecting the service; private actors who may be related to the service in a variety of roles, such as donors or as indirect recipients of the services provided as is, for example, the case of organizations employing ex-clients; public or private actors with service provision roles that complement the services provided.

3. Build a quality assessment partnership representing different stakeholders and perspectives

Typically, service quality assessment does not involve a proper partnership. Most often, if not always, it is initiated by the management of the service and may or may not involve in a greater or lesser role service staff.

Building an assessment partnership that extends beyond the management and the staff of the service is not an easy task. However, it represents an important condition for bringing into the assessment the perspectives of the different actors involved and paving the way for utilising the results of the assessment in practice. Clients are the group with the most direct interest in the service; they have the strongest claim for being involved in the assessment of service quality and therefore qualify for being represented in the assessment partnership. Involving them from the start gives the message that their perspective of the service will be taken seriously.

4. Conduct an informal review of the service before embarking in a full assessment

Once the service setting to be assessed is chosen, relevant actors are identified and there is an assessment partnership in place, it is strongly recommended to conduct an informal review of the service as a preparatory step before proceeding to a full, empirically based, service quality assessment.

The review will provide a preliminary assessment of the quality of the service This assessment will be limited in scope and depth, but the review will help to map in more detail the field of the service to be assessed; to identify in a systematic way issues, questions and hypotheses that should be examined; to locate relevant sources of information; and to anticipate potential difficulties and problems.

The conceptual framework developed by the project, offers a working agenda that can guide the review. The framework puts forward a set of dimensions, that are generic, i.e. not specific to any particular type of service and adaptable to a wide range of social public services. At the end of the review this set of dimensions will have been revised, tailored to the circumstances of the service being assessed and the perspective of the actors involved, and could serve as the definitive agenda for the full assessment.

5. Proceed to an empirical investigation

The informal service review of the service will have produced a preliminary assessment of service quality and must have enriched considerably the understanding of the quality of the service and the different issues involved. Nevertheless, it will be limited in scope and depth by the subjective nature of the views on which it is based and by the absence of empirical and systematic evidence. For a proper and valid assessment it is important to collect systematically the views of the relevant stakeholders, at least of staff and clients, and to exploit relevant documentary or statistical information. For these reasons it is strongly recommended to proceed to a full-scale, empirically based, service quality assessment.

The key in this stage is to identify the sources of relevant information and determine the method through which to collect this information in relation to the definitive assessment agenda already set. The Service Quality Assessment Guide offers a procedure and examples for doing this.

Locating relevant documentary and statistical data is quite straightforward, except possibly in the case of documentary data where the confidentiality of the personal data of clients that information should be respected. In contrast, tapping the views of the groups involved (staff, clients and others) through a survey is a more complex task. It represents the core element of the service quality assessment and requires a certain amount of resources, appropriate competences, and care in its planning and implementation.

6. Organise carefully the survey of relevant actors

Conducting the survey involves choices and options that should be considered carefully before proceeding. The way the survey will be conducted, its target groups and the way they will be approached and asked to respond, the type and content of the questions that will be asked, and the way the findings of the survey will be communicated; will determine whether the groups approached will respond or respond truthfully, the validity of the conclusions that will be drawn from its findings, and the impact its findings and the assessment as a whole may have on the service that is being assessed.

Choices concern primarily two aspects: first, determining the survey respondents, i.e. the groups of actors who will be targeted by the survey; second, designing the survey method, i.e. the means that will be used to collect information from the respondents.

7. Choose the survey respondents

In the case of staff, there is not much room for choice, except in relation to the numbers involved, the methods used, and the resource requirements involved. As a rule, all members of staff should be included, i.e. professional staff, administrative staff, as well as support and blue-collar staff. Different categories of staff, or indeed different staff professions, perform different functions and relate in different ways to service clients. Their experience of the service may be delimited by their function and role, but their view of the service in valuable and should be tapped by the assessment.

In the case of clients, there is usually more room for choice. When considering choices for this group it should be borne in mind that apart from clients who are the direct recipients of the service at the time of the assessment; there are two other groups that should be considered as potential respondents: first ex-clients; second, client parents and relatives or other parties with client guardianship roles, for example a social worker responsible for a person who is treated by a mental health service.

Ex-clients may be difficult to reach or they may be less willing to respond. Including them in the survey will add to the resources needed, but their contribution may be very important in the case of certain services. It will be especially important in the case of services with significant dropout rates; in those cases, the dropout rate represents in itself an important service aspect related to service quality and the reasons for it should be examined by the assessment. The contribution of ex-clients will also be important when the benefit of the service for the client is materialised after the client leaves the service, and therefore post-service information is relevant to service quality and should be included in the assessment. Of course, there may be services where the issue of ex-client does not arise although these are likely to be quite rare. Except in such cases, it is strongly recommended to include ex-clients in the survey.

There are circumstances, where including in the survey parents, relatives or third parties with guardianship roles, is dictated by the condition of the clients, i.e. when clients do not have the capacity to respond because of their mental condition or very young age. In those situations, clients should be represented in the survey by parents or relatives. There are also circumstances where parents and families are also direct recipients of services, in which case they should be included in the survey along with clients. Nevertheless, even if neither of these circumstances is present, it may be worthwhile to include parents or relatives in the survey, if practically feasible, as they may enrich the assessment by offering a complementary view of the service from a different, but important, perspective.

Hydrokinetic therapy in the swimming pool

8. Choose the survey methods

Designing and conducting a survey requires a minimum of competence in empirical research, regarding designing questionnaires, approaching respondents, analysing the data, etc.; and if there is not enough empirical research competence available within the service, it is recommended that external assistance is sought.

An important choice is between face-to-face interviews and self-completion of questionnaires. Face-to-face interviews have the advantage that they provide more rich and qualitative data but they need more resources and they run the risk that responses may be biased.

This is more likely the stronger the dependence between service provider and client. When the option of face-to-face interviews is chosen, it is important that the interviewer is someone from outside the service and in no circumstances someone with a direct authority-dependence relation with the respondent. The respondent should see the interviewer as being independent of the management of the service and as being able to guarantee the confidentiality of the views of the respondent. This requirement applies equally whether the respondent is a member of staff or a client.

In contrast, self-completion of questionnaires requires fewer resources, makes confidentiality much easier and minimises bias, but limits the scope for qualitative data. To compensate for this shortcoming, in the case of self-completion, respondents should be encouraged to use open questions as much as possible.

Two more points are worth mentioning. The first concerns maximising comparability of responses between different groups, where possible. This is typically the case, when clients and staff are asked to state their views about the same issues, i.e. concerning facets of their interaction or facets of the service experienced by both sides. In those cases it is recommended to use the same questions and standard scales that facilitate comparison (e.g. the Likert scale or numerical rank scales). The second point is to treat the survey not as a sophisticated, theory-led, academic exercise but as a practical tool for understanding in a systematic and valid way the state of service quality from the different perspectives of those involved and as a basis for initiating practical action.

9. Brief the survey respondents

Conducting a survey of service quality among service staff and clients is a delicate task and care should be taken to respect legitimate sensitivities, either from the staff or the clients. The staff may feel threatened by an exercise that will give the opportunity to their clients to say what they think about their work and professional competence; both staff and clients may suspect the motives behind the assessment.

Establishing an assessment partnership and involving staff and clients from the start will go a long way for alleviating suspicion of ulterior motives, but the kind of the questions that will be asked and respondent anonymity will also be important in gaining the trust of the respondents.

Nevertheless, proper care and time should be taken in preparing the ground for the survey by briefing properly all those who will be asked to respond to the survey. Failure to do that may result in a low response rate, compromise the validity of the survey findings, and minimise the potential for utilising the outcome of the assessment to improve the service. Staff and clients should be informed in writing as early as possible about the assessment, its objectives and the way it will be conducted. Ideally both groups should also be briefed orally when that is practically feasible, e.g. depending on the numbers involved and the circumstances of the service; in most cases it should be possible for the staff to be briefed in staff meetings where they will have the opportunity to express their views on the whole assessment exercise and on specific aspects of the survey.

In both cases there should be a clear statement of the purpose of the survey and the use that will be made of it when the questionnaires are administered. In both cases, respondents should received a summary of the findings and conclusions soon after the completion of the survey and have access to the conclusions of the assessment as a whole.

10. Follow-up the assessment

There should be follow-up of the service quality assessment but the way this could be done will depend on the particular circumstances of each service and also on the results of the assessment itself. Under no circumstances, the assessment should be seen as an one-off exercise, it should be treated as a starting point for initiating action and improving the quality of the service, and as a vehicle for empowering clients and strengthening their position as partners in the process of service provision.

Replicating the staff and client survey or an abridged version in regular intervals (e.g. every two or three years) should also be considered; it is a useful means for monitoring developments and progress and for establishing service quality assessment as an integral part of the service structure.

REFERENCES

- Albrecht, G. L. (1999) The Disability Business: Rehabilitation in America. Chicago: Sage

- Bank-Mikkelsen, N. E. (1999) Historische Entwicklung und eine Zukunft mit Perspektiven. In: Max Kreuzer (ed.) Behindertenhilfe und Sonderpadagogik. Erfahrungen und Praxisbeispiele aus Danemark. Berlin: Luchterhand

- Barnes, C. (1991) Disabled People in Britain and Discrimination. London: Hurst and Co

- Barnes, C. and Mercer, G. (2003) Disability. Cambridge: Polity Press

- Barnes, C. and Mercer, G. and Shakespeare, T. (1999) Exploring Disability. A Sociological Introduction. Cambridge: Polity Press

- Bengtsson, S. (1997) "Quality by Users' Influence and Involvement in Denmark - The Logical Development of Social Services". In A. Evers, R. Haverinen, K. Leichsenring and G. Wistow (eds.) Developing Quality in Personal Social Services. European Centre Vienna: Ashgate

- Bengtsson, S. (2000) "A Truly European Type of Disability Struggle: Disability Policy in Denmark and the EU in the 1990s" in European Journal of Social Security, vol 2, issue 4, 2000/2001

- Bengtsson, S. (2002) Quality of Life and Quality in Services for People with Disabilities. Paper for the Danish Disability Seminar. Copenhagen: The Danish National Institute of Social Research

- Bengtsson, S. (2003) "Overcoming goal displacement and power displacement in social service provision" in Scandinavian Journal of Disability Research, vol. 5 no. 3 pp 262-280.

- Bickenbach JE, Chatterji S, Badley EM and Ustun TB (1999) "Models of disablement, universalism and the international classification of impairments, disabilities and handicaps" in Social Science & Medicine 48:1173-87.

- Commission of the European Communities (2003) Equal opportunities for people with disabilities: A European Action Plan. COM(2003) 650 final. Brussels: Commission of the European Communities

- Commission of the European Communities (2005) Situation of disabled people in the enlarged European Union: the European Action Plan 2006-2007. COM(2005) 604 final. Brussels: Commission of the European Communities

- Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation.

http://europa.eu.int/comm/employment_social/soc-dial/labour/78ec/ad_en.pdf

- Council of the European Union (2004). Joint report by the Commission and the Council on social inclusion. Brussels: Council of the European Union

- Daly, M. (2002) Access to social rights in Europe. Council of Europe: Strasbourg

- Definitions of disability in Europe.

http://www.brunel.ac.uk/depts/govn/research/Disability.htm

- Degener, T. and Quinn, G. (2000) "A Survey of International, Comparative And Regional Disability Law Reform". From Principles to Practice: An International Disability Law and Policy Symposium, October

- Department of Health (2001) Valuing People. A New Strategy for Learning Disability for the 21st Century. A White Paper. London: Department of Health

· EASPD (2005) Social Services of General Interest in the European Union. Specific characteristics of the Disability sector. Brussels: EASPD (www.easpd.org)

- European Commission (2001). Disability and social participation in Europe - 2001 edition. Luxembourg: Office for Official Publications of the European Communities

- European Commission (2002) Definitions of Disability in Europe. A Comparative Analysis. Brussels: European Commission/Directorate-General for Employment and Social Affairs

- European Council (2000) Lisbon presidency conclusion. European Council: Brussels

- Evers A, Haverinen R, Leichsenring K and Wistow G (eds) (1997) Developing Quality in Personal Social Services: Concepts, Cases and Comments. Aldershot: Ashgate

- Evers, A. (1995) "Cash and care". In Die Grunen Hessen: Gepflegt versichert - Versichert gepflegt. Tagungsdokumentation, 1995

- Evers, A. (1997) "Quality Development - Part of a Changing Culture of Care in Personal Social Services". In A. Evers, R. Haverinen, K. Leichsenring and G. Wistow (eds) Developing Quality in Personal Social Services. European Centre Vienna: Ashgate

- Evers, A. and Haverinen, R. and Leichsenring, K. and Wistow, G. (Ed.) (1997) Developing Quality in Personal Social Services. Concepts, Cases and Comments European Centre Vienna: Ashgate

- Freyhoff, G. et al. Included in Society. Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People (www.community-living.info)

- Giedenbacher, Y., Stadler-Vida, M. and Strumpel, C. (2003) Stakeholders' perspectives of quality in Supported Employment. An evaluation manual. Vienna: European Centre for Social Welfare Policy and Research

• Goffman, E. (1963) Stigma. Prentice-Hall: Englewood Cliffs, New Jersey

• Good, A (2003) The ICF and Disability Research. SAI conference paper. April 2003, Revised July 2003

• Grammenos, S (2003) Illness, Disability and Social Inclusion, European Foundation for the Improvement of Living and Working Conditions: Dublin

• Koch-Nielsen, I and Treebak, I (1998) Quality in Social Public Services: Concepts and Measurement, European Foundation: Dublin

• Lindqvist, B. (1999) Lindqvists nia - nio vagar att utveckla bemotandet av personer med funktionshinder. Stockholm: Socialdepartementet SOU 1999:21

• Lipsky, M. (1980) Street-Level Bureaucracy. Dilemmas of the Individual in Public Services. N.Y.: Russel Sage Foundation.

• Morris, J. (1993) Independent Lives? Community Care and Disabled People, Macmillan:Basingtoke

• Ness, S. and W?rness, K. (1997) Rationality and Management in Public Care Services. In: A. Evers, R. Haverinen, K. Leichsenring and G. Wistow (eds.) Developing Quality in Personal Social Services. European Centre Vienna: Ashgate

• OECD (1996) Service Quality Initiatives in OECD Member Countries, Background paper for eponymous symposium by the secretariat of the OECD Public Management Service (PUMA), Paris, November

• OECD (2003). Behindertenpolitik zwischen Beschaftigung und Versorgung. Ein internationaler Vergleich. Frankfurt/New York: Campus Verlag

• Oliver, M. (1990) The Politics of Disablement. Basingstoke: Macmillan.

• Oliver, M. (2002) "Using Emancipatory Methodologies in Disability Research", paper presented to the first NDA/Centre for Disability Studies Annual Disability Research Seminar, 3 December 2002, Dublin

• Oliver, M. and Barnes, C. (1998) Disabled People and Social Policy. London: Longman.

• Olsen, H. (2002) Attitudes towards the Disabled in Denmark. The Danish Disability Council. Danish National Institute of Social Research 02:14

• Oorschot, W. van and Hvinden, B. (2001) "Introduction: towards Convergence? Disability Policies in Europe". In Oorschot, W. van and Hvinden, B. (Ed.). Disability Policies in European Countries. The Hague: Kluwer Law International, pp. 3-12.

• Pillinger, J. (2001) The Quality of Social Public Services: European Synthesis Report, European Foundation: Dublin

• Pillinger, J. (2004) Towards Best Practice in disability health services, National Disability Authority: Dublin

• Pollitt, C. (1997): Business and Professional Approaches to Quality Improvement: A Comparison of their Suitability for the Personal Social Services. In: A. Evers, R. Haverinen, K. Leichsenring and G. Wistow (eds.) Developing Quality in Personal Social Services. European Centre Vienna: Ashgate

• Rajavaara, M. (1997) "Professionals and Quality Initiatives in Health and Social Services". In A. Evers, R. Haverinen, K. Leichsenring and G. Wistow (eds.) Developing Quality in Personal Social Services. European Centre Vienna: Ashgate

• Rieper, O. and Mayne, J. (1998) "Evaluation and public service quality" in Scandinavian Journal of Social Welfare, no 7: 118-125

• Schadler, J. (2002): Individuelle Hilfeplanung - Schlussel zur Modemisierung de Behindertenhilfe. In H. Greving (Hg.) Hilfeplanung und Controlling in der Heilpadagogik, Freiburg im Breisgau: Verlag Lambertus

• Schalock, R. L. (ed.) (1996) Quality of Life, Vol 1. Conceptualisation and Measurement. Washington: American Association on Mental Retardation.

• Sevenhuisjen, S. (1998) Citizenship and the Ethics of Care, Routledge: London

• Shakespeare, T. (2000) "The Social Relations of Care" in Lewis, G., Gewirtz, S. and Clarke, J. Rethinking Social Policy, Sage: London

• Stone, D. (1984) The Disabled State. Temple University Press, Philadelphia

• Tomas, C. (1999) Female Forms. Experiencing and understanding disability. Buckingham, Philadelphia: Open University Press.

• Tronto (1993) Moral Boundaries: A Political Argument for an Ethic of Care, Routledge: London

• United Nations (1993) Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. New York: United Nations

• WHO (2001) ICF: International Classification of Functioning, Disability and Health. Geneva: WHO

• Williams (2001) "In and Beyond New Labour: Towards a New Political Ethics of Care" in Critical Social Policy. 21 (4), no 69

• World Health Organization (2002) Towards a Common Language for Functioning, Disability and Health. Geneva: WHO