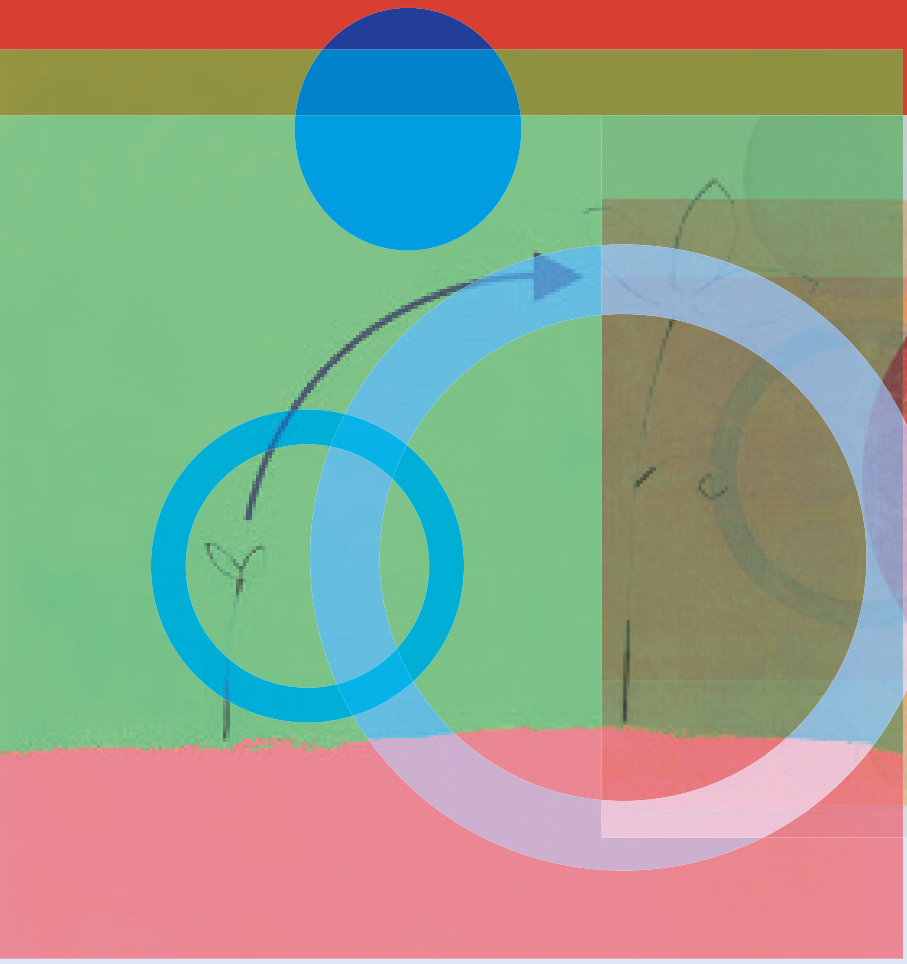
Enhancing rights and inclusion of ageing people with disabilities and older people with disabilities: a European perspective



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Enhancing rights and inclusion of ageing people with disabilities and older people with disabilities: a European perspective

Report

Council of Europe, 2009

French version:

Renforcement des droits et inclusion des personnes handicapées vieillissantes et des personnes âgées handicapées : une perspective européenne

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Preface

From 1959 to 2007, disability-related activities were carried out within the legal and financial framework of the Partial Agreement in the Social and Public Health Field, established by Resolution (59) 23 and revised by Resolution (96) 35, with 18 member states (2007).

The work was steered by the Committee on the Rehabilitation and Integration of People with disabilities (Partial Agreement) (CD-P-RR) and its Bureau, and carried out by several subordinate committees of experts. It resulted in the elaboration of about 60 resolutions with policy recommendations to member states, adopted by the Committee of Ministers in its composition restricted to the member states of the Partial Agreement, and in the publication of about 60 reports and comparative analyses, providing useful instruments for the transfer of know-what and know-how as well as for social benchmarking.

The idea to expand the Council of Europe disability-related activities from the Partial Agreement in the Social and Public Health Field with 18 member states to all Council of Europe member states was first launched at the Malaga Ministerial Conference on Disability in 2003. The year 2006 saw the adoption of the Council of Europe Disability Action Plan 2006-2015 (full title: Recommendation Rec(2006) 5 on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015) and of the terms of reference of the European Co-ordination Forum for that Plan (CAHPAH), which held its first meeting in 2007. As from 1 January 2008, all disability-related activities have been carried out within the Council of Europe Programme of Activities for all member states. This expansion is a great political achievement and shows the clear commitment of the Organisation and its member states to the protection and promotion of the rights of people with disabilities in Europe.

The promotion, implementation and follow-up of the Plan are overseen by the European Co-ordination Forum for the Council of Europe Disability Action Plan 2006-2015 (CAHPAH). The Forum is a multidisciplinary committee of disability experts from all 47 member states, the observer states, various Council of Europe bodies and committees, and several international organisations both governmental and non-governmental. It is a real multi-stakeholder co-ordination body facilitating the mainstreaming of disability issues in all relevant policy areas in the Organisation and its member states. Also represented are the European Commission and International Organisations, such as OECD, ILO, UNESCO, UNHCR, UNICEF, and WHO. Working relations have been established with the Office of the High Commissioner for Human Rights (OHCHR) and the EU Agency for Fundamental Rights (FRA). The European Disability Forum (EDF), which has participatory status with the Council of Europe, represents people with disabilities and their families or organisations.

The Forum is assisted in the implementation of the Disability Action Plan by a number of subordinate committees. The Committee of Experts on ageing of people with disabilities and older people with disabilities (CAHPAH-VPH), a subordinate body of the Forum, investigated the specific situation of people with disabilities as they age and of older persons who become disabled due to old age. The present report is the result of the work of this committee. The initial draft was prepared and reviewed by Professor Brian Munday, Keynes College, University of Kent, Canterbury, United Kingdom.

Executive summary

This report is part of the Council of Europe's ongoing work to help improve the quality of life of people with disabilities in Europe. The report presents the situation of two related groups, namely ageing people with disabilities and older people with disabilities. These groups have consistently been neglected in the development of social rights, policies and social support services.

The substance of the report results from an analysis of replies to a questionnaire distributed to member states of the Council of Europe, using the following structure:

Legal framework with special reference to promoting autonomy and an independent life; enhancing the quality of services; ensuring equal access to social services and legal protection;

Financial framework including rights and funding for services, diversification of sources of finance, and the challenge of financial restraints;

Participatory framework concerning involvement at different stages in planning and implementation of policies, programmes and services;

Operational framework covering a range of measures and services to promote autonomy and independence for disabled people, with emphasis on innovation and good practice;

Individual framework including measures to prepare people with disabilities for change and transition; needs assessment and service planning for individuals; and measures to guarantee rights to be fully informed and consulted.

The report sets the analysis within a concise elaboration of principal topics that are the background and context of the Council of Europe's project, namely:

– demography;

– fundamental principles;

– the Independent Living Movement and the social model of disability;

– the United Nations Convention on the Rights of Persons with Disabilities;

– the Graz Declaration on disability and ageing;

– the "personalisation" agenda in European social services;

– different starting points;

– resource constraints.

Not all countries were able to respond to the questionnaire so that this report is an indication of the situation across member states, rather than being a comprehensive account.

1. Introduction

This report has been produced by the Committee of Experts on ageing of people with disabilities and older people with disabilities and builds on the Council of Europe's extensive programme of work in the field of disability. Specifically, it contributes to the project "Improving the quality of life of people with disabilities in Europe" and relates closely to the Council of Europe Disability Action Plan 2006-2015. This work is fundamental to the Council's core emphasis on human rights, the Council being the only intergovernmental organisation where disability issues are dealt with from a human rights perspective.

The report is based substantially on an analysis of responses to a questionnaire distributed to all member countries of the Council of Europe, taking due note of the main Terms of Reference for the Committee of Experts. In summary these were:

1. To produce a report on the current situation of ageing people with disabilities and older people with disabilities, with examples of good practice and innovative experiences;

2. To produce recommendations for members states concerning:

   – social service and programmes promoting autonomy, independent and active living for people with disabilities;

   – measures to enhance quality of services;

   – measures to enhance equal access to social services and legal protection.

The recommendations of the committee were adopted on 8 July 2009 as Recommendation CM/Rec(2009)6 of the Committee of Ministers to members states on ageing and

disability in the 21st century: sustainable frameworks to enable greater quality of life in an inclusive society.

1.1. Ageing and older people with disabilities

The term "disability" hides a wide range of disabling conditions, with an equally wide range of origins, causes, consequences and support needs. As the Graz Declaration on Disability and Ageing[1] indicates:

> *People with disabilities are a diverse group including people with physical, sensory, intellectual disabilities, developmental disabilities, people with mental health problems as well as with complex and multiple disabilities as outlined in the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001).*

The term "ageing and older people with disabilities" is used in this report to refer to two distinct but related groups of people that share certain characteristics but who are also different in some respects. The first group refers to people who grow older having experienced a disability for much of their lives, sometimes from birth. For the second group, disability is ordinarily experienced at a relatively advanced age, dementia being but one example. Older people with disabilities may, for example, suffer sudden fractures for which he/she is unprepared. They may experience new communication difficulties, reduced empowerment and disabling mental disorders. New learning processes are required to begin to cope with disability. People ageing with disabilities already have tools for communication and movement but undergo a change in pace and environment. They may have difficulty in fitting into facilities for elderly persons without a disability.

1. The Graz Declaration on Disability and Ageing. Graz, Austria, June 2006.

Ageing and older people with disabilities' experiences will sometimes differ considerably between countries so that generalisations should be treated with caution. To varying degrees, national policies and services will reflect the different characteristics, needs and service requirements of individuals within the two groups. Some examples are found in this report.

1.2. Added value

The Committee of Experts was well aware that much work had already been done with more underway in the broad field of disability. The intention of the committee has been to produce a report with useful added value within a major aspect of disability that has received relatively little attention until recent years. The Council's Report "Citizens not Patients"[2] comments that "Until now disability policy in Europe has been predominantly concerned with the needs of disabled people of working age in relation to rehabilitation and employment, but there is growing concern about the increasing prevalence and severity of disability in childhood and older age" (p. 15).

In their study on ageing people and physical disability Oliver and Zarb[3] argued that people ageing with disabilities had been more or less completely overlooked. That situation has changed with more people living longer into older age, together with medical advances that enable people with life long disabilities to live longer than previously. Overall, the size of this group of people with disabilities has been rising considerably in most or all societies. There has also been relatively little information relating to the needs of this group. They have generally not received a very high priority in the provision of support services, with

2. *Citizens not patients: developing innovative approaches to meet the needs of disabled people*. Council of Europe, 2004.
3. Zarb, G. and Oliver, M. (1993) *Ageing with a disability: what do they expect after all these years?* University of Greenwich, United Kingdom.

evidence as they get older they may well suffer the double disadvantage of being both old(er) *and* disabled.

The committee's report adds to a growing volume of reports and other publications on the particular circumstances and support needs of these two related groups of people with disabilities. Its emphasis is on examples of what is being done in member states of the Council of Europe to develop legislation, policies and social support for citizens whose rights and support needs have historically been neglected.

2. Background and context

The Committee of Experts identified major topics that are part of the background and context for the subject of their particular project in the field of disability. They are summarised as follows.

2.1. Fundamental principles: from "disabling services" to "supportive environment"

In their research on people with physical disabilities Oliver and Zarb found that most of the people ageing with a disability "do not want to make any great demands on support services. Rather, they simply want to get on with their lives secure in their knowledge that what little support they may need will be available if and when they need it." Some fundamental principles form the basis of two very different approaches to providing support for ageing and also older people with disabilities. One approach is a paternalistic, discretionary, system-led approach based on disabling services that have taken too little notice of people's views and experiences. The other approach is the reverse with an emphasis on a supportive environment and the rights and real participation by people with disabilities. These approaches are elaborated in some detail in Oliver and Zarb's report. In outline they are:

Disabling services include:	*Supportive environment* includes:
• dependency • fixed options • discretionary services • reactive • service-led support • anxiety • partial solutions	• independence • choices • rights and entitlements • proactive • user-led support • security • creative solutions

Countries' approaches to the design and implementation of support for ageing and older people with disabilities need to be increasingly modelled on the latter rather than the former system. Oliver and Zarb refer to the "building blocks" that help to facilitate the development of the *supportive environment* system. These include: information; knowledge; confidence; personal support; financial resources; and empowerment. The writers conclude:

> *This, in turn, points to the most important component of a supportive environment – namely, a framework of rights and entitlements. All of the problems which define the disabling environment are fundamentally linked to the basic issue that services are mostly provided on a discretionary basis and that older people with disabilities have very few rights (p.94).*

2.2. Demography

The increased longevity of people with disabilities has been referred to. The global trend towards ageing societies is most pronounced in Europe where by 2050 approximately 35% of the population will be over the age of 60, compared with 20% in 2002. Worldwide life expectancy at birth has increased by 20% from 1950-2002. European men aged 60 can now expect to live another 17 years, 22 years in the case of women.

One consequence of clear demographic trends will be significant increases in the number of older people with disabilities, including people suffering from varying degrees of dementia. The need for health and social care support will be that much greater at a time when families are declining in size with fewer adult siblings available to provide informal care and support to dependent older family members.

2.3. The Independent Living Movement and the "social model of disability"

People with disabilities have increasingly taken the lead in campaigns to establish their rights to be recognised as equal citizens and to determine the types and ownership of services that they require. This is illustrated in the growth of the independent living movement.[4] worldwide whose goals are the full embodiment of disabled persons' rights to equality, freedom and dignity. It challenges much traditional thinking, policy and service provision relating to disability. The social model of disability puts emphasis on the disabling environment that prevents the person with disabilities from enjoying the full rights of citizenship. Persons with disabilities will point out that the struggle is ongoing.

2.4. The Council of Europe Disability Action Plan 2006-2015

On 5 April 2006, the Committee of Ministers adopted Recommendation Rec(2006) 5 on the Council of Europe Action Plan to promote the rights and full participation in society of people with disabilities: improving the quality of life of people with disabilities in Europe 2006-2015. The Recommendation Rec(2006)5 is addressed to all 47 member states of the Council of Europe. The Council of Europe Disability Action Plan 2006-

4. See, for example: Gillinson, S., Green, H., and Miller, P. *Independent Living. The right to be equal citizens*. Demos, United Kingdom (2005).

2015 has a broad scope, encompassing all key areas of the life of people with disabilities. These key areas are duly reflected in 15 action lines which set out key objectives and specific actions to be implemented by member states. The action lines are the core of the Action Plan. They cover areas ranging from participation in political and public life and participation in cultural life to information and communication, education, employment, vocational guidance and training, community living, social protection and legal protection, etc. Every action line stresses the need to ensure that the rights of people with disabilities are secured and promoted by the member states through specific actions.

2.5. The United Nations Convention on the Rights of Persons with Disabilities

The point has been made that much work has been and is being done towards ensuring that people with disabilities enjoy full rights of citizenship in all countries. Most member states of the Council of Europe report they have signed the UN Convention on the Rights of Persons with Disabilities.[5] This commits countries to, for example:

– develop and implement policies, laws and administrative measures for securing a range of fundamental rights for all age groups for whom disability is an issue;

– abolish laws, regulations, customs and practices that constitute discrimination;

– guarantee that persons with disabilities enjoy their inherent right to life on an equal basis with others;

5. The UN Convention on the Rights of Persons with Disabilities and its Optional Protocol were adopted by the United Nations General Assembly in December 2006, and opened for signature in March 2007. The Convention entered into force on 3 May 2008.

– ensure that persons with disabilities are able to live independently, are included in the community, choose where and with whom to live and have access to in-home, residential and community support services.

There are mechanisms to help ensure that countries honour their obligations under the Convention. Each country designates a focal point in government to promote and monitor implementation, and submits periodic reports on progress with implementation. An 18-article Optional Protocol on Communications allows individuals and groups to petition the UN Committee on the Rights of Persons with Disabilities once all national recourse procedures have been exhausted.

The UN Convention provides an important framework and support for national and European-wide movements – including that of the Council of Europe – to establish and advance full rights of people with disabilities.

2.6. The Graz Declaration on Disability and Ageing

The Graz Declaration of 2006 is a particularly important contribution to the European-wide commitment to enhancing the rights and removing barriers to inclusion of ageing and older people with disabilities. The Declaration was the work of the European Conference on Ageing and Disability – Disabled People are Ageing, Ageing People are Getting Disabled, held in Graz, Austria, on 8 and 9 June 2006. The conference was organised by a network of European ageing and disability NGOs. The Declaration is based on the principles of inclusion and human rights and is a wide ranging statement with detailed recommendations and proposals addressed to the European Commission, member states, social and civil actors, and national and international organisations.

The Declaration should be consulted for its many recommendations and proposals. The following are some of its important introductory statements on the main subject:

– the positive, active aspects of ageing should be emphasised, for example, ageing is associated with the development and acquisition of experience, wisdom, competence and respect. These developments and values apply equally to ageing people with disabilities;

– greater prominence should be given to concepts of healthy and active ageing;

– ageing and disability will be the test for inclusiveness of European societies for the decades to come, with community living and independent living being key elements on that journey;

– people with intellectual/learning disabilities need special attention in policy planning, systems of support and rights. This group now enjoys a similar life expectancy to the general population but has been neglected in national policies and programmes of support;

– policies tend to be focused only on the issue of *care*, disregarding necessary policy reforms for developing mechanisms for participation and independence;

– Europe is only at the beginning of a learning process about old age. The fundamental challenge is to make the shift from the “welfare state” to the “welfare society” that will accord equal rights and be fully inclusive for older citizens with disabilities.

2.7. The “personalisation” agenda in European social services

The aims of disabled people are supported by the development of the personalisation agenda in social services in growing numbers of European countries. The personalisation agenda

implies that services are “tailor-made” to suit the individual. One of the means is to introduce personal budgets for social services users to enable them to purchase directly services that they choose as best suiting their needs and circumstances. Funding is progressively shifted from service organisations to individual users, including people with disabilities. Examples are provided in this report. As the later discussion of personal budgets recognises, direct payments and personal budgets can have disadvantages for many people with disabilities for whom they are neither suitable nor their preferred route for appropriate services.

2.8. Different starting points

Member states of the Council of Europe are not on a “level playing field” in terms of ensuring full rights for people with disabilities in their countries. For example, some have well-developed social and health care systems while others have only been able to introduce modern services in relatively recent years. Understanding of and attitudes towards disability have accordingly developed differently in the countries. The economic situation of countries also differs very considerably. This affects not only levels of government funding for direct services but also the length of time it may take to effect expensive but necessary changes to make the physical environment and a country’s transportation system fully accessible for people with disabilities, as well as supply necessary services and support.

2.9. Resource constraints

All countries face the challenge of how to fund the quantity and quality of social, health and other forms of support needed to ensure that people with disabilities have full access to their rights as citizens in modern societies. There is an extensive international literature on “the problems of the welfare state” and how countries are, for example, developing mixed economies of welfare to maximise financial and service contributions from the

not-for-profit, for-profit and informal (family, friends, neighbours) sectors, alongside the crucial contributions of governments and their agencies. This applies in the disability field where the demographic trends will result in escalating levels of need for social and health care support in coming years, alongside rising expectations by people with disabilities. Resource constraints will be a reality for the foreseeable future, requiring the setting of priorities and an ever stronger commitment to do justice to the neglected needs of ageing and older people with disabilities.

As one commentator[6] observes on the situation in the United Kingdom, a situation that will also apply to other countries:

> *The UN Convention comes into force, however, at a time when two opposing agendas are in collision. On the one hand there is the government's much trumpeted individualisation agenda of choice and user-led care planning; and on the other is the depressing practical reality of squeezed budgets, tightening eligibility criteria, increased charging and new resource allocation schemes that promise significant cuts in funding for those in most need.*

2.10. The questionnaire

The committee of experts circulated a questionnaire to all member states of the Council of Europe. Replies were received from 20 countries providing material for much of what follows in this report. The main subjects covered by the questionnaire were

1. the legal framework
2. the financial framework
3. the participatory framework
4. the operational framework

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6. *Conventional wisdom,* Luke Clements. Article in "Community Care" pages 30-31, 5 June 2008.

5. the individual framework.

As the report shows, each main subject was divided into sub-subjects. A key consideration has been to try to identify the extent to which countries differentiate in policies and provision between the two groups of people with disabilities. Respondents were encouraged to provide examples of good practice and innovations which might be of relevance to other countries. In following the subject structure of the questionnaire the report has to make selective rather than comprehensive reference to countries' responses. Quoting good practice or innovation in one country does not mean, of course, that it is not also found in other countries.

3. Legal framework

3.1. Introduction

The Council of Europe has done previous substantial work on legislation relating to disability, as evident in the book "Legislation to counter discrimination against persons with disabilities".[7] That project helpfully identified three main legal approaches of countries: anti-discriminatory legislation; preferential treatment; and compensatory measures.

> *Anti-discriminatory legislation takes a concept of equality as its point of departure…Preferential treatment may take a variety of forms, such as the different quota systems which exist in some countries. Compensatory measures consist of various rules and regulations aimed at compensating for a disability (p.123).*

7. *Legislation to counter discrimination against persons with disabilities* (2nd Edition 2003) Council of Europe Publishing, Strasbourg.

All three approaches may be applicable in relation to ageing and older people with disabilities. Reference has been made to the importance of the UN Convention on the Rights of Persons with Disabilities. Rights specified in the Convention are those that come into force immediately (for example, the prohibition of discrimination and the right to equal treatment) and rights that are to be progressively achieved (for example, the right to accessible transport, inclusive education). The latter rights are not immediately binding. Countries that ratify the Convention will need to develop their national legislation relating to disability in line with the Convention's provisions but with many provisions taking some time to pass into legal requirements.

3.2. General legislation concerning rights of people with disabilities

Responses to the questionnaire indicated that legislation in the disability field tended not to refer specifically to ageing and older people with disabilities, but had a wider reference. For example, Belgium has a law of 2007 to combat *all* forms of discrimination and a decree of 2004 to guarantee equal treatment in the labour market. Much general legislation applies to persons with disabilities of all ages, and aims to abolish discrimination of various kinds, for example, both the Estonian and Finnish Constitutions were amended in the 1990s to include a non-discrimination clause – including on the grounds of disability. Most if not all other countries have similar clauses in their constitutions. The French Constitution includes – as do others – the positive right for people with disabilities to have access to the fundamental rights granted to all citizens; and to be treated equally in all parts of the country.

This reference to "all parts of the country" has a wider relevance. In countries with a federal structure and degrees of regional autonomy it can be more difficult to ensure that uniform standards of access to rights apply across the whole country. For example, Bosnia and Herzegovina is a country with certain

centrally determined legislation applying across the country, but with different regulations applying between cantons. People with disabilities have equal access to services and legal protection but because of the complexity of the country's structure, administrative obstacles and the overloading of the courts, people – including people with disabilities – very often cannot access those services and protection.

Turkey passed a wide-ranging law in 2005 designed to improve the rights of people with disabilities in line with international norms. This law aims to prevent disability; to ensure the health, education, rehabilitation, employment, care and social security requirements of people with disabilities; to take measures to remove obstacles preventing participation in society; and to coordinate all relevant services. A subsequent project "Turkey without Barriers" aims to raise awareness across all sectors about the provisions of the law, using a variety of methods to convey the message throughout society.

The Netherlands respondent comments "The constitution decrees that everyone is entitled to equal treatment but the reality is sometimes different. People with a disability or chronic illness often receive unequal treatment, particularly at work, school or in public transport". This situation may well be found in a number of other countries.

3.3. Legislation promoting autonomy and an independent life

There were many references in the responses under this heading to legislation and other measures. Croatia has a national strategy to guarantee equal opportunities for people with disabilities, including measures to enable people to have control over their own lives; to enable them to live independently; and to emphasise their abilities rather than impediments. "Individualisation" is an important principle in the national strategy.

The Spanish Law of 2006 promotes the personal autonomy and care for dependent persons. It does so through the creation of a personal autonomy and dependence care system and a guarantee from central government that there will be a minimum core of rights for all citizens in all parts of Spain.

A purpose of Norway's Social Services Act is "to contribute to giving individuals opportunities to live independently and to achieve an active and meaningful existence in community with others". All services included within the scope and chapters of the law are intended to promote autonomy and independent life for people of all categories – including people with disabilities.

Personal assistance, direct payments and personal budgets

Personal autonomy and independent living for people with disabilities have been greatly enhanced by the introduction of measures to enable them to purchase their own personal assistance and support, rather than having to fit into whatever services happened to be available. Croatia initiated a pilot project in 2006 to provide *personal assistance* to the most severely disabled persons. The Netherlands has a system of *personal budgets* for social services, a scheme introduced in legislation in 1996. Depending on the outcome of an individual assessment, a person with a disability may be allocated a sum of money to spend on care services of their choice. This puts the service user in a position closer to the person shopping in the high street, able to choose between various services depending on quality, convenience, price, etc.

Norway has a scheme for "user-managed personal assistance to people with severe disabilities", introduced in 2002. People with disabilities are probably the main beneficiaries of this move to progressively allocate funding to users themselves, a movement that will spread to an increasing number of European countries in the next few years. Of course, direct payments and the

employment of a personal assistant do not suit all persons with disabilities – particularly older people and people with particularly disabling conditions such as dementia. The same caveat applies to personal budgets compared to the more traditional model of assessment followed by services available from the service organisation(s).

3.4. Legislation enhancing the quality of services

The Social Welfare Act in Estonia includes a wide range of measures, such as a right to good standards of service. There is a system of monitoring/inspection, with powers for suspension of defaulting service providers. Several countries have legislation covering required qualifications of staff working in social care, and on supervision and standards of private services. Georgia has legislation on standards and norms of services. The professional training of social workers and others working in this field is a high priority.

The Netherlands' 1996 Care Institutions Quality Act includes four requirements care providers must fulfil:

– institutions must provide "responsible care";

– they must make clear what they will do to achieve and maintain that responsible care;

– they must systematically protect and improve the quality of care they provide;

– they must publish an annual report elaborating the quality control policies they have applied, and reports on the quality of care they have delivered.

A special issue in many countries concerning a guarantee or uniformity in quality of services is local autonomy. Norway is a good example. There is a National Quality Regulation of social

services, mentioning different values and ideals that services should fulfil. But there are no minimum standards set for the services, except for general legal principles that people should be given necessary health and social care. Municipalities have considerable freedom to set standards themselves according to political choices and the local economy.

Slovakia does not currently have legislatively regulated quality standards for social services but there are other measures that have some influence on quality. Sweden has a proposal for a "dignity guarantee for health and social care for older people". This will clearly set out what all elderly care will have to offer and what the elderly person and his/her family members can expect. Proposals are being considered for service or quality levels that must always be met, with particular emphasis on the frailest people who are unable to represent themselves.

3.5. Legislation enhancing equal access to social services and legal protection

Many countries have measures to help ensure access of *all* groups to social services, not only people with disabilities. In some cases, such as in Latvia, general policies of equal opportunities have special application in relation to disability, for example, the Latvian Unit of Equal Opportunities Policy for the Disabled. The same point about general measures applies concerning legal protection. A commitment to implement the UN Convention and national laws prohibiting discrimination help to ensure equal access to all services – including social services – and provide a degree of legal protection.

An example of general measures is in the Netherlands where the right to equal treatment has been incorporated into various laws, for instance, equal treatment of men and women, general equal treatment. Both direct and indirect discrimination are prohibited, although there are particular circumstances when discrimination *is* allowed. The Dutch contribution comments on the many new

equal treatment rules and regulations drawn up at the European Union and national levels which have led to a complex system of equal treatment legislation not always transparent to third parties.

The introduction of an *Ombudsman* system in several countries provides a valuable means of redress and protection for social services users who consider, for example, that they have not had equal access to social services. Such a system was introduced in Croatia in 2007 with an Ombudsman specifically for people with disabilities, but Ombudsman systems are mostly generic rather than specific to a particular group. Citizens can appeal to the Ombudsman when they consider they have been wrongly dealt with by a service, providing a valuable addition to other safeguards for the rights and interests of service users – including people with disabilities. It can be argued that an Ombudsman system should be established in every European country.

4. Financial framework

There are several mostly closely related issues that affect the funding of social support for ageing and older people with disabilities:

– *Financial constraints.* Reference was made earlier to difficulties all countries face in providing sufficient funding for social care – including support for people with disabilities of all ages. These funding pressures will continue.

– *Rights and funding for services.* The cost of implementing certain kinds of rights must always be met by governments, such as, for instance, people's democratic right to vote. But other rights may be conditional, with implementation depending upon affordability criteria, for example, a person's right to the most effective drug in

health care. The drug may be too expensive given the level of health care funding available. Similarly with funding for implementing rights in the disability field – some rights may be absolute with more-or-less guaranteed funding, but others may be conditional.

– *Diversification of sources of finance.* Governments at all levels are seeking to share the costs of social support with an increasing range of non-governmental funders. These alternative sources of finance include: contracting out services to for-profit and not-for-profit service providers; charging service users – and sometimes their families – for all or part of the cost of a service; lottery and gaming finance; national and international donors, such as, for instance, the George Soros Fund. The growth of charging or "co-payments" has become a major feature of social support systems, raising ethical and more pragmatic issues over what services should be free of charge for all (for instance, the provision of wheelchairs) and what services should reasonably be means tested.

As was illustrated in responses to the questionnaire, all these and other issues affect the financing of social support for ageing and older people with disabilities. Countries without long-established social welfare systems can face particular challenges in funding adequate levels of social support.

Sources of funding for disability services and support

In Belgium, there is a combination of state and small personal contributions for service costs. In Bosnia and Herzegovina, "all state measures directed to persons with disabilities and older persons are financed from public budgets and funds of health, pension and invalids insurance". People needing orthopaedic aids pay an average of 50% of the cost, which in some cases can amount to 60-80% of a person with disabilities' annual income.

In Estonia, users pay a percentage of service costs based on income, while in Georgia they pay 30-50% depending on the type of service. For older people in Finland, payment is an average of 20% of the full cost of service. In long term care the charge is a maximum of 80% of income. Special services are mostly free. Latvia has a system of whole state funding for certain benefits and services, such as, technical aids, vocational and social rehabilitation. When there are charges for service users there are variations between municipalities. Similar variations between municipalities are found in Norway but the home nursing service is free. In Sweden special measures for people with disabilities are free of charge, with a few exceptions, for example, someone in residential care with special services may be charged reasonable fees for accommodation, recreation and cultural activities.

In Ukraine, in certain circumstances, relatives of dependent persons have to contribute towards the cost of services. It is not entirely clear if the law obliges family members to provide care and support themselves, or rather to pay part of the service provided by others to the dependent relative. Similar family obligations apply with the care costs for an elderly relative in some other countries (for example, France).

Being able to enter the labour market and earn an income is an important aspect of personal autonomy and an independent life for people with disabilities. Countries provide various types of special funding to enable people to work, and to support them – and their employers – when people with disabilities are employed. The funding arrangements in Latvia are an example where there is state support for employee training, subsidies for employers to create jobs for people with disabilities, and for making the workplace accessible. Similarly, there is some relief for the cost of fares for people with disabilities who have extra costs to travel to work and subsidies to the transport system to enable people to travel to health clinics, rehabilitation centres,

etc.. If taxis are necessary then only the cost of equivalent public transport is payable.

Most public funding for disability services and support comes from central and local governments. In Latvia, the state co-finances with municipalities the setting-up of new facilities, with a tapering of the state's contribution after year one. NGOs are prominent in the disability field, funded to varying degrees by central and local governments. In Croatia and Finland, there is funding for disability organisations from takings of slot machines. Elsewhere, lottery money is available. Many central and eastern European countries receive funding from international donors to develop both state and NGO services for people with disabilities.

Finally, people with disabilities may obtain some income tax relief towards the cost of payments for necessary services. In France, there are tax allowances for employing a home assistant, while "An important aspect of the Dutch system is that if a person pays more than a certain amount for their care related costs, the tax system allows them to deduct costs from their annual income". In Turkey, there is VAT exemption for purchases of some assistive devices and exemption from property tax on one owned house.

5. Participatory framework

People's participation in the planning, provision and evaluation of services that affect them has become a subject of major importance in Europe. The relative powerlessness of the service user dependent upon rigid, non-participatory systems of inflexible state bureaucracies is being transformed by several trends in European society.[8] Also, the traditional paternalistic "daddy knows best" dominance of the service professional is changing to a more open, democratic relationship with users that encourages

8. See *Report on user involvement in personal social services,* Council of Europe, 2007.

their active participation in the service relationship and process. Progress with citizens' participation is more advanced in some countries than others, reflecting the earlier reference to "different starting points".

Changes are particularly evident in the field of disability with the emphasis on rights, independence and equality. Particular issues have been – and still are – tokenistic participation, and participation in the form of representation by able-bodied persons (for example, from NGOs) rather than direct involvement by persons with disabilities themselves. There is a hierarchy of participation, with user control of services as the pinnacle of real participation.

The predominant type of participation reported in responses to the questionnaire is the involvement of people with disabilities and their associations/NGOs on various governmental and other bodies responsible for policy, legislation and service planning. Some examples include: NGOs involved in forming legislation, regulations etc. concerning disability (Armenia); associations of people with disabilities participating fully in forming policy documents, public hearings on disability issues (Bosnia and Herzegovina); national and municipal councils on disability with NGO representation (Finland); strong representation on National Consultative Council of People with Disabilities, with similar representation at Departement level (France); representation on committee for co-ordination of social inclusion policy (Latvia). Moldova encourages participation through meetings with individuals, use of complaints systems, and meetings/round tables with associations and groups of older people with disabilities.

It is difficult to know how effective these types of representation are for people with disabilities – and particularly for ageing and older people with disabilities. As indicated above, it is most acceptable to people with disabilities themselves when they are personally participating, rather than being represented by able

bodied people in NGOs. However, personal participation is not straightforward in the case of people with certain disabilities such as dementia. Participation does have to be tailored to the capabilities of different groups of persons with disabilities.

Other forms of reported participation include: councils of elders involved in management of retirement homes (Armenia); in some areas some services are run by users and their organisations (Bosnia and Herzegovina). A different but very positive form of participation by people with disabilities is through *volunteering,* emphasising their capacity for active involvement rather than being seen as passive recipients of services. A good example is found in Ukraine:

> *On the initiative of the Ukrainian veterans a volunteer movement was launched in the country and a Co-ordination Council on Development and Promotion of Volunteering was created, headed by the Minister of Labour. At present over 450,000 older persons are engaged in volunteer activities at the local level, providing free services for over 600,000 veterans.*

The availability of easily accessible *information* is a basic necessity if ageing and older people with disabilities are to participate effectively. Ukraine is an example of countries using the mass media to inform and invite views. Internet sites are increasingly used as a source of information on rights and sources of social support. A basic question that has to be addressed is how or in what forms can information best be made available to maximise opportunities for ageing and older people with different types of disabilities to participate?

Both Croatia and Latvia indicate full and comprehensive participation by people with disabilities at different levels in planning and implementing programmes that affect them. Croatia acknowledges that the change to the social model of disability has been particularly influential in promoting greater participation

by persons with disabilities. User surveys are mentioned (for example, Estonia, Latvia and Norway) as principal means for evaluating the participation of ageing and older people with disabilities at the different stages in the development of services. An important question here concerns the extent to which persons with disabilities are fully involved in the design of the user surveys.

Numbers of ageing and older people with disabilities are unable to be actively involved in their communities and live outside their own home. Consequently, some may live rather isolated, lonely lives with very limited, if any, contact with family, friends or neighbours. The following is an example of a municipality in the Netherlands that attempts to reach out to isolated individuals in the community:

> *The municipality of Almelo started a pilot project in 2004 on Perspective with personal budgets for welfare in Almelo. Chronically ill inhabitants living in social isolation can receive a personal welfare budget of €450 maximum for "tailor-made" leisure activities. A home visit can be made to take care of neglected needs of the person concerned, needs related to social protection benefits and/or home care.*
>
> *This simple approach is efficient in many respects. It stimulates chain co-operation between organisations of care and welfare, while the beneficiaries/clients recover, improve and restart their participation in society according to their own wishes and possibilities. Thanks to the personal welfare budget, inhabitants are reached, who tend towards isolation, depression and serious health deterioration. Within the target group people with both physical and psychiatric problems ask for treatment and other forms of help.*
> www.geluksbudget.nl/?action=PGb-Welzijn-Almelo,
> accessed 9 June 2009

6. Operational framework

The comment was made earlier that people with disabilities "just want to get on with their lives" but this may not be easy for many ageing and older people with disabilities. Understandably, they may find it difficult to pursue their rights and apply for services because of a lack of energy or reasons of language, sickness or shyness. Therefore, at some point many ageing and older persons with disabilities will need access to good quality social support services suited to their specific needs. These services may be residential or home/community based and provided by governmental or non-governmental providers.

It is important that necessary standards are specified and implemented, together with mechanisms for users to provide feedback and to make formal complaints. Services in the disability sector need to show that they are informed by and based upon "good practice" requirements articulated by persons with disabilities themselves, with a particular emphasis on support that empowers and enables independent living.

"Operational" framework covers a wide range of service provision. It is not helpful to provide descriptive lists of such services. Instead, this report concentrates on some information and examples of countries' approaches to key aspects of operational provision.

6.1. Quality assurance and protection of rights

Belgium has established mandatory quality management for institutions and other services for people with disabilities. Quality assurance concepts and charters are in place in all rest and nursing homes. Croatia has similar systems in its gerontology centres for elderly and older people with disabilities. Belgium also has a charter concerning the sexual and emotional needs of

people with disabilities and a working group on elder abuse. There are comprehensive individual action plans for each person with a disability, and regular user satisfaction surveys. Ukraine has introduced independent advocacy into boarding houses, along with public boards of trustees to ensure outside scrutiny of service standards and compliance with users rights.

It is important that systems are in place for people with disabilities to appeal against decisions affecting them in some way, for instance, because of poor service standards, or denial of rights. In Estonia, for example, citizens may appeal to the county governors against social services decisions made by municipalities. Earlier reference was made to the importance of Ombudsman systems to enable aggrieved citizens to complain/appeal against actions by public authorities. In Estonia, "The Ombudsman exercises oversight to ensure that public authorities and officials observe the law and fulfil their duties in the discharge of their functions. The aim is to ensure good administration and the observance of constitutional and human rights". The Ombudsmen in other countries have a similar function, for example, in Finland.

Croatia has a 2008 Ombudsman for Persons with Disabilities Act to protect the rights of persons with disabilities and improve implementation of international conventions and treaties. In 2006, Norway introduced a National Ombudsman for New Equality and Anti-Discrimination as part of a range of measures to ensure greater rights protection.

6.2. Innovations and good practice

These are relative terms in that what is an innovation in one country may be long established practice in another country. Similarly there may be differing views about what constitutes good practice in this field.

Employment opportunities. It is important to provide opportunities for ageing people with disabilities to engage in employment. In Belgium, people can go into rest and nursing homes while at the same time they have opportunities for employment as well as for assisted recreation.

Deinstitutionalisation and the provision of good quality community-based services are widely regarded as progressive and good practice. This is the policy in Ukraine and in the Netherlands where the emphasis is on prevention, an active life-style, volunteering opportunities and small group homes rather than large-scale institutions. As an important step in deinstitutionalisation, Ukraine has opened the All-Ukrainian Center for Professional Rehabilitation of the Disabled and is developing training for social workers and other professionals.

Deinstitutionalisation is also the strategy for Croatia's social welfare system, including disability services. There are several examples of innovative community-based services. Croatia has a long tradition of foster care, mostly for children and young people but also adults, including persons with disabilities. There are regional variations in the amount and type of foster care provision. Croatia is one of many countries providing small group homes, particularly for people with learning disabilities. Typically, four or five persons live in the same home with occasional professional help with social, working, cultural, recreational and other fundamental needs of living.

Deinstitutionalisation and integration rather than separation is a policy priority in the Netherlands, a country that has undergone a cultural shift in attitudes and practices concerning disability. Previously, it was thought that good practice required special separate facilities but that was not what people with disabilities themselves wanted. Now there is a Disability and Society Taskforce whose remit is to make clear that no one should be excluded or separated from mainstream society. This involves a

change from compensating for limitations to adapting living and working environments to accommodate needs of all.

Changes in approaches to the design and building of accommodation are central to policies of inclusion for ageing and elderly people with disabilities. In the Netherlands on "the government estimates that in the next ten years at least 225,000 no-step-dwellings (dwellings without staircases) will be needed. These will be newly-built or adapted accommodation. In 14% of these dwellings there must be a point of support in the neighbourhood from which care can be provided." Similarly in the United Kingdom, all newly-built accommodation will have to be designed to be fully accessible for people with disabilities. Turkey has a target of making all public buildings fully accessible by 2012.

Use of information technology, including Internet. Norway has different portals and web addresses with examples of good practice, including those in relation to disability. Disability and Ageing (FOA) has published a book "Inclusion in Practice" which includes a range of helpful information and examples of good, innovative practice concerning people with disabilities in employment. Another book (2007) includes stories of people with disabilities showing their successes and ways of functioning in working life.

Estonia started implementing "e-inclusion" strategies which means both inclusive ICT and the use of ICT to achieve wider inclusion objectives. It focuses on participation of all individuals and communities in all aspects of the information society, such as, e-government, e-health – and, presumably, social services.

Personal Assistants. Earlier reference was made to this type of scheme where people with severe disabilities receive a cash benefit to enable them to employ their own individual personal assistant. This is probably one of the most important benefits for people with disabilities to enable them to live more

independently. Norway has had such a scheme since 2000, which all municipalities must provide and finance. The service user recruits and directs the assistant on a 24-hour basis as necessary. Relatively few people use this service in Norway, less than 2,000 in 2006.

6.3. Challenges, opportunities and plans

Estonia reports some problems of accessibility to services for people with disabilities, the main challenges being to ensure non-discrimination of all people with disabilities, ensuring equal treatment and support for independent living. But the biggest challenge is to change attitudes of people who are elderly and disabled so that they become active members of society.

Georgia needs to develop its services in disability, including ensuring physical accessibility, and to promote high quality service standards through national standards. The demand for services will grow annually with cost implications that will require more flexible and feasible financing arrangements.

Latvia's concerns include a lack of co-operation across services – a challenge for most countries – and the need for greater environmental accessibility such as in housing. Not all aspects of functioning and disability are applied in disability assessment; work places are not sufficiently adapted for the needs of people with disabilities; services in municipalities are underdeveloped with institutions still too dominant; and greater resources are needed for the training of specialists in municipalities.

In Norway, standard service provision may be inadequate in quantity and quality, partly because of staffing difficulties which are likely to increase.

Staffing social services generally is a widespread issue across Europe and the subject of a major research project and

publication by the European Foundation for the Improvement of Living and Working Conditions.[9]

The main challenges facing Slovakia include: absence of specialised care for older people with special problems; insufficient domestic care; poor co-ordination of home-based and institutional care; and insufficient care of carers of relatives with disabilities.

Latvia has detailed plans representing opportunities to develop a wide range of their services. Slovakia reports extensive work in one city to integrate the needs of people with disabilities into programmes of economic and social development. They are attempting to institute a model of "community social work" to initiate and co-ordinate efforts in this field.

In Ukraine, employment opportunities for people with disabilities are increasing steadily. There is also a new system of territorial social services centres at the local level for elderly people and people with disabilities.

Countries are at different stages in plans to improve the quantity and quality of their services for the increasing numbers of older people suffering from dementia. Norway's plans are one example of comprehensive planning across a range of related services in relation to dementia:

> A comprehensive plan for people with dementia: The Dementia Plan 2015
>
> This is in the context of a plan for improving services for all citizens in the municipalities, including enhancing quality of health and social services.

9. *Employment in social care in Europe,* Office for Official Publications of the European Communities: Luxembourg 2006.

The plan has several elements:

– models for day care and activities;

– improved housing and other accommodation;

– improved integration of specialist services and municipalities services in diagnostic work;

– information and support groups for relatives;

– more widespread information about dementia;

– development of training programmes for staff;

– establishment of an interactive databank of experiences in the field.

7. Individual framework

Previous sections of this report have been concerned with rights, legislation, participation and social support services for ageing and older people with disabilities as groups or collectives. The focus in this section is upon *individuals* and how countries personalise their range of provision to people within these two groups.

7.1. Case management[10]

One of the most significant developments in the individualisation or personalisation of social services has been the introduction of "case management". This is a form of social support service in

10. See Banks, P. (2004) "Case management" in Nies, H. and Berman, P. (eds) *Integrating services for older people: a resource book for managers*, European Health Management Association, Dublin.

which a case manager – sometimes but not always a social worker – works collaboratively with an individual ageing or older person with a disability and his/her carers to assess their needs and form an agreed service plan in response to these needs. A package of services is put into place and its implementation monitored and periodically reviewed by service user and case manager. Services in a package may come from various sources with cost limits depending on the size of the case manager's budget.

Several countries report the use of case management in this field:

– Belgium uses it for assessment of need and service planning;

– Estonia refers to how "every service provided is based on individual assessment and problems addressed using case management methodology";

– Spain has a law of 2006 which introduced the "personal care plan" intended to provide the most appropriate response to the needs of each dependent person.

Other countries may not refer directly to care management but state that the individual service user's needs and wishes must be taken into account in deciding on services, for example, in the case of Bosnia and Herzegovina.

France's "life project" for the individual is an interesting and unusual term. "The multi-disciplinary team in the department centre for people with disabilities assesses the person's needs in accordance with his/her life project". As a result, the Commission for the Rights and Independence of People with Disabilities may take new decisions when new needs come to light. One of the attractions of the life project is that it seems holistic in concept and is applied to people of all ages and circumstances and is reassessed as necessary.

7.2. Other approaches to individualisation

Prevention is a key objective in several initiatives. In Finland, social and health professionals make preventative visits to older persons who are not service users but who are at risk in some way (for example, lonely persons, persons with multiple diseases, recently bereaved persons) and who may need information and support to enable them to continue with their independent living. In Georgia, occupational therapists and other professionals in day care services help people with disabilities to cope with major changes in their circumstances. Crisis centres in Latvia help people recover their physiological and social stability.

In Norway, there are courses to prepare elderly people with intellectual disabilities for old age, courses on coping with bereavement, preparing for retirement, facing illness, and also for carers of dependent relatives. Slovakia offers preventative health examinations, an increasing spread of domiciliary care, support for carers and information on healthy living. There is an intriguing project “I am 65+ and I’m glad I’m living healthily”. People with disabilities leaving residential care are prepared for coping with life in the community, along with help for any family members.

Slovakia is also introducing “individual development plans” in a new draft act on social services. “The draft sets a duty for a provider to plan the course of a social service according to personal objectives, needs and abilities of a recipient and to keep written individual records of the course of provision of social service”. This is to be done in co-operation with the service user where he/she is capable, or with the participation of his/her legal representative.

Sweden also has a range of preventative measures similar to those mentioned above and also has clear procedures to safeguard the rights of individual service users, for instance, to

have access to and read all the information in any personal files compiled by municipal or independently run social services.

8. Conclusion

This report completes the first of two tasks stipulated in the Terms of Reference for the Committee of Experts. The report has formed the basis for completion of the second task, namely the formulation of recommendations for members states concerning:

– social service and social protection programmes promoting autonomy, independent and active living for ageing and older people with disabilities,

– measures to enhance quality of services,

– measures to enhance equal access to social services and legal protection.

Recommendation CM/Rec(2009)6 of the Committee of Ministers to members states on ageing and disability in the 21st century: sustainable frameworks to enable greater quality of life in an inclusive society was adopted on 8 July 2009 and is available at www.coe.int.

Fundamental to the committee's findings is the all important principle of *equal rights* for ageing and older people with disabilities. Failure to recognise and implement this right is at the heart of a history of discrimination and neglect in this field.

An important second principle with major practical implications is that of *mainstreaming*. The Council of Europe Disability Action Plan 2006-2015 states that "Mainstreaming involves integration of services for people with disabilities with those for other citizens." This applies to services for ageing and older people

with disabilities, while recognising – as the Action Plan states – that “Mainstreaming does not preclude the existence of disability-specific policies, where they are in the best interests of persons with disabilities.” Here, “policies” should be taken to include “services”.

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