

## Council of Europe Report

# Council of Europe actions to promote the rights and full inclusion of ageing people with disabilities

*Angela Garabagiu, Administrator, Integration of People with Disabilities Division Directorate General of Social Cohesion, Council of Europe, F - 67075 Strasbourg, France*

*Correspondence to: Angela Garabagiu, Integration of People with Disabilities Division Directorate General of Social Cohesion, Council of Europe, F - 67075 Strasbourg, France, Phone: +33 (03) 90 21 45 20, Fax: +33 (03) 88 41 27 26, E-mail: [angela.garabagiu@coe.int](mailto:angela.garabagiu@coe.int); [disability@coe.int](mailto:disability@coe.int)*

## Introduction

Taking note of the current demographic situation in Europe, immediate action is required to improve the quality of life of ageing people with disabilities and older people who may develop disabilities as they age.

In International conventions and policies it is recognised that all human beings are of equal worth and that this should not be affected by the existence of a disability, regardless of its nature or its degree or by any other factor, such as ageing, nationality or income. People with disabilities and ageing people are citizens who have the same rights and duties and who should have the same opportunities as others to govern their own lives. The rights of people with disabilities are grounded in several human rights frameworks, including the UN Convention on the Rights of Persons with Disabilities, which entered into force on 3 May 2008. These frameworks are based on the universal respect for human rights and fundamental freedoms for all without distinction.

## Council of Europe Disability Action Plan 2006–2015

On 5 April 2006, the Committee of Ministers adopted the Recommendation Rec (2006) 5 on the Council of Europe's "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" [1]. The Recommendation is addressed to all 47 member states of the Council of Europe. The Council of Europe Disability Action Plan 2006–2015 promotes the paradigm shift from a health-related to a social and human rights-based approach to disability: from the patient to the citizen. It also promotes the essential concept that disabled people and their representatives need to be consulted as stakeholders in decision-making processes which affect

their lives, from national policy design to more individual subjects.

The Council of Europe Disability Action Plan 2006–2015 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 the following areas:

- No. 1: Participation in political and public life;
- No. 2: Participation in cultural life;
- No. 3: Information and communication;
- No. 4: Education;
- No. 5: Employment, vocational guidance and training;
- No. 6: The built environment;
- No. 7: Transport;
- No. 8: Community living;
- No. 9: Health care;
- No. 10: Rehabilitation;
- No. 11: Social protection;
- No. 12: Legal protection;
- No. 13: Protection against violence and abuse;
- No. 14: Research and development; and
- No. 15: Awareness raising.

Every action line stresses the need to ensure that rights of people with disabilities are secured and promoted by the member states through specific actions.

The Disability Action Plan refers to the human rights of particularly vulnerable groups of people with disabilities under its '**Cross-cutting aspects**':

Within the European disabled population there are people with disabilities who face specific barriers or experience two-fold discrimination, e.g. children and young people with disabilities, women and girls with disabilities, people with disabilities in need of a high level of support, ageing people with disabilities and people with disabilities from minorities and migrant

communities. They have a higher risk of exclusion and generally have lower levels of participation in society than other disabled people. These specific groups of people with disabilities require a horizontal response to ensure their inclusion in society.

The ageing of people with disabilities, particularly those requiring more intensive support due to the nature of their impairment, presents new challenges for societies across Europe. This includes support for individuals and for their families especially where elderly parents are the main carers. Innovative approaches are required to meet these challenges across a wide range of policy and service areas.

## The findings of the Committee of Experts on ageing of people with disabilities and older people with disabilities

The Council of Europe Committee of Experts on ageing people with disabilities and older people with disabilities analysed the current situation in a number of European countries and produced a report and recommendations, covering a wide range of policy areas. The analysis focused on the following frameworks: **legal** (with special reference to promoting autonomy and independent life), **financial** (including rights and funding for services, and diversification of sources of finance), **participatory** (involvement at different stages in planning and implementation of policies, programmes and services), **operational** (covering a range of measures with an emphasis on innovation and good practice), and **individual** (including measures to prepare people for change and transition, needs assessment and service planning on an individual basis).

The findings of the Council of Europe's Committee of Experts on ageing of people with disabilities and older people with disabilities have resulted in a report on 'Enhancing rights and inclusion of ageing people with disabilities and older people with disabilities: a European perspective', the initial draft of which was prepared and reviewed by Professor Brian Munday, Keynes College, University of Kent, Canterbury, United Kingdom. The recommendations on 'Ageing and disability in the 21st century: sustainable frameworks to enable greater quality of life in an inclusive society' have been finalised by the Committee of Experts and have been submitted for adoption, together with the report, to the European co-ordination forum for the Council of Europe Disability Action Plan 2006–2015 (CAHPAH)<sup>1</sup>.

<sup>1</sup> The report and recommendations mentioned in this paragraph are not yet published (May 2009), but can in time be found at the website of the Council of Europe: <http://www.coe.int/>

The term 'ageing people with disabilities and older people with disabilities' refers 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 one example.

As one member of the Committee stressed, member states and NGOs should take account of the differences between people with disabilities who age, and elderly people affected by disability, when service provision is being put in place:

On one hand, **elderly persons who become disabled** may in general receive the same services as other elderly persons and remain in what was their own circle of family and friends (often their children).

The person, and his/her environment, must be provided with:

- prevention to forestall 'disabling' developments in their situation (intellectual, motor and sensory, as well as psychological);
- training of a specific nature, for example in communication: however, this training and these techniques must be adapted to extreme age: too late to learn Braille or sign language;
- rehabilitation activities (e.g. groups to maintain the faculty of memory);
- bodily but above all mental care to stimulate relational activity and especially activities for retaining and stimulating the capacities exercised in one's earlier occupational life.

On the other hand, **an ageing person with a life-long disability** often faces specific fractures:

- decease of parents;
- unsuitability of the services which he/she received through adult life: staff of the services assisting children or adults with disabilities are competent to ensure constant progress of the persons they assist, not to deal with situations of decline or end-of-life;
- frequent impossibility of acceptance in the services and 'homes' for elderly persons (frequent rejection by the other elderly inmates).

These people must, therefore, be offered:

- continuity of family-type or inclusive support;
- access to specific services;
- small accommodation units separate from but close to those of ageing relatives;
- increased services, which should be placed on a mutual basis (and which usually cannot be delivered under the same conditions of personal independence as at an earlier age).

Finally, the diversity of disabilities must also be considered:

- E.g.: mental disabilities cause great difficulty for family life or for inclusion in groups where disparate situations of disability intermingle;
- Mental disabilities often require special stimulation if accelerated regression is to be avoided.

Building bridges between services provided to these groups of people is important. At the same time, however, the specific needs of each individual should be the primary reason for deciding on the type of services offered.

## The report

### Legal framework

A sound legal basis for the establishment of rights and entitlements is of great importance in this field. Rights should be legally defined and enforceable. The United Nations Convention on the Rights of Persons with Disabilities is a major policy instrument. It is important to note the difference between 'rights with immediate effect' and 'rights to be progressively introduced'.

Questions of equity in rights and entitlements arise in countries with a federal structure where regions may have high degrees of autonomy. Rights and entitlements may vary from one region to another, whereas in countries with centralised systems the same entitlements and standards of support for ageing and older people with disabilities should apply across the whole country. Sometimes complex questions arise as to what should be decided centrally for the whole country and what can be left for regional/local decisions. For example, it can seem unjust for there to be different legislation, requirements and standards of care services for elderly people with disabilities in residential and nursing care homes in different areas of a single country.

A crucial element in legislation in this field is to promote and ensure a variety of support measures for ageing and older people with disabilities, designed to enable them to live as independently as possible. For example, many countries have legislation to provide *personal assistance* and *direct payments*. The measures are closely related, providing finance as of right to individuals to purchase their own care and support arrangements.

Legislation to introduce an *Ombudsman* system in several countries has been important in providing a valuable means of redress and protection for social services users.

## Finance

Findings from the project's questionnaire revealed familiar issues and dilemmas for member states: increasing budgetary constraints on social expenditure; competition between major services, such as health and social services; competition between services for different age groups e.g. between those for younger and older people. These issues and dilemmas point to the difficult question as to which rights are or should be *absolute* and which ones can reasonably be considered as *conditional*. The former have to be honoured and paid for by governments for all citizens concerned, whereas conditional rights are usually dependent upon decisions of affordability by the responsible authorities.

It is clear that governments are looking to diversify and extend sources of funding to meet the cost of implementing rights of ageing and older people with disabilities. Increasing longevity makes this ever more urgent. The report showed there to be a considerable variation in sources of funding, including state, regional/local government, not-for-profit organisations, international donors, lotteries—and individual users and their families.

The trend towards increasing 'co-payments' is noticeable. When governments' funding is under stress then funding for services and support may be targeted on the poorest and most vulnerable people, leaving others to pay a proportion or even all of the cost of a service.

## Participation

People's participation in the planning, provision and evaluation of services that affect them has become a subject of major importance in Europe—particularly in the disability field. Paternalistic models of service provision are being replaced with more open, democratic relationships with users that encourage their active participation in the service relationship and process.

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 (e.g. 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 following are some of the most important points from the Committee's work:

- The availability of easily accessible information is essential if ageing and older people are to participate effectively

- Forms of participation must be suitable and adapted to the capabilities of people with different forms of disability
- There are many examples across Europe of people with disabilities being involved in planning and decision-making processes at different levels, ranging from users involvement in residential care homes to participation at central government level
- Participation by ageing and older people with disabilities in volunteer schemes is a particularly positive development (e.g. intergenerational solidarity projects)

### **Operational framework, including support services**

Ageing and older people with disabilities are by no means always able to 'get on with their own lives' as they would like to do. 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. At some point they 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. Some aspects of these support services are highlighted

- Quality assurance and quality management should be an essential feature of these services
- Service users' rights should be clearly specified in charters that are constructed with full participation by users themselves
- An independent advocacy service and an appeal system (e.g. an Ombudsman) should be available and easily accessible

Nevertheless, countries report that significant challenges remain to be addressed. These include: deep-seated attitudes of passivity by service users and paternalism of service providers; the need to recruit and retain sufficient numbers of properly trained staff; to ensure widespread rather than piecemeal availability of services across a country; need for closer cooperation and integration between services e.g. health and social services; and the availability of sufficient funding.

### **Individualisation**

Rights, legislation, participation and social support services are frequently considered as relating to ageing and older people with disabilities as *groups* or *collectives*. But, in line with the personalisation agenda in social care, the Committee gathered information on how countries *individualise* support for the two groups of people with disabilities.

One approach is through the *case/care management* service model. 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. 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. This type of individualised service has become quite prevalent in Europe.

Countries focus on the needs and personal circumstances of individuals through a range of *prevention* measures. These include visits by social support staff to individuals who are seen as being at risk e.g. because of bereavement. Visiting and befriending services—often carried out by volunteers—can be very important to the well being of individual older persons with disability who live alone. Prevention can also include either courses or direct work with individuals to help prepare them for major life changes such as leaving residential care to live in the community, or preparing for retirement.

### **Recommendations**

The Recommendations on 'Ageing and disability in the 21st century: sustainable frameworks to enable greater quality of life in an inclusive society' are grouped under three headings. All refer specifically to ageing people with disabilities and older people with disabilities:

- 1) Promoting autonomy and an independent and active life;
- 2) Enhancing the quality of services;
- 3) Enhancing equal access to social services and legal protection.

Given the relevance of the provision of services aimed at improving the quality of life of ageing people and people with disabilities, several recommendations with regard to the quality of services are referred to in this section.

- 2.1. "It is essential that services of sufficient quality *and* quantity are provided;
- 2.6. The quality of services depends heavily upon a workforce of sufficient quantity, with a range of personnel trained to meet the competence requirements of their particular roles and tasks. Their consequent professionalism should then be recognised and properly remunerated;

- 2.9. Rights to good standards of services provided by all service providers should be defined and guaranteed in legislation, with means for redress clearly specified. Areas to be covered include: training and qualifications of staff; required standards in specific services; systems for monitoring and inspection; complaints systems;
- 2.10. Quality assurance and management systems and methods that take account of ethical considerations and professional standards are appropriate in this field and should be used in these services;
- 2.11. Quality holistic services give proper attention to more than physical needs. As appropriate they should respond to people's cultural, emotional, sexual and spiritual needs;
- 2.12. Quality is enhanced when services are individualised through means such as comprehensive individual action plans for each person with a disability.”
- To sum up, innovative approaches and co-ordinated action, which can respond to specific needs with the aim of enabling ageing people with disabilities to remain in their community to the greatest extent possible, are needed. This requires a careful assessment of individual needs and forward planning as well as the availability of adequate services.

## Reference

1. Council of Europe. Recommendation Rec (2006) 5 of the Committee of Ministers to member states 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. Council of Europe; 2006. Available from: [http://www.coe.int/t/e/social\\_cohesion/soc-sp/Rec\(2006\)5%20Disability%20Action%20Plan.doc](http://www.coe.int/t/e/social_cohesion/soc-sp/Rec(2006)5%20Disability%20Action%20Plan.doc)

## Related information

Websites: <http://www.coe.int>; [http://www.coe.int/t/dc/files/themes/handicap/default\\_en.asp](http://www.coe.int/t/dc/files/themes/handicap/default_en.asp)

Easy to read version of the Council of Europe Disability Action Plan 2006–2015 available from [http://www.coe.int/t/e/social\\_cohesion/soc-sp/integration/02\\_council\\_of\\_europe\\_disability\\_action\\_plan/Council\\_of\\_Europe\\_Disability\\_Action\\_Plan.asp#TopOfPage](http://www.coe.int/t/e/social_cohesion/soc-sp/integration/02_council_of_europe_disability_action_plan/Council_of_Europe_Disability_Action_Plan.asp#TopOfPage)

Presentation slides from the 1st International Conference on Bridging Knowledge in Long Term Care and Support available from: [http://www.bridgingknowledge.net/Presentations/SympA\\_Garabagiu.pdf](http://www.bridgingknowledge.net/Presentations/SympA_Garabagiu.pdf)