

COUNCIL OF EUROPE

COMMITTEE OF MINISTERS

RECOMMENDATION No. R (98) 9

OF THE COMMITTEE OF MINISTERS TO MEMBER STATES ON DEPENDENCE

*(Adopted by the Committee of Ministers on 18 September 1998
at the 641st meeting of the Ministers' Deputies)*

The Committee of Ministers, under the terms of Article 15.b of the Statute of the Council of Europe,

Considering that the aim of the Council of Europe is to achieve a greater unity between its members for the purpose, *inter alia*, of facilitating their social progress;

Considering that the demographic situation in Europe is characterised by low fertility rates and increasing life expectancy, resulting in an ageing society; that people are living longer in good health, while the number of chronic diseases – a potential factor of dependence – is increasing; that the traditional family is changing, with the emergence of smaller families and an increasing number of single-parent families; that the interdependence between generations is changing and that the individual, the family and society will have to adapt to this new situation;

Considering that these factors have an effect on the phenomenon of dependence and lead to an increasing need for help for dependent persons, calling for public action to contend with this social risk;

Considering “dependence” as a state in which persons, by reason of lack or loss of physical, psychological or intellectual autonomy, require significant assistance or help in carrying out their usual day-to-day activities;

Considering that the principle of autonomy for the dependent person must be a guiding factor in every policy concerning dependent persons;

Bearing in mind that policies concerning old age, disabled persons, health, the family and employment have implications for the approach to be adopted to the problem of dependence;

Considering that cover for the contingency of dependence should be an integral part of every social protection system;

Considering that it is the responsibility of the public authorities to ensure the quality of care given;

Considering the importance of appropriate training for carers, given the skill required to play their role to the full;

Considering that it is important to reinforce the social protection of carers;

Considering the importance of giving appropriate assistance to carers without professional status in order to provide them with relief from and help with their responsibilities, which require them to be available to a significant degree;

In view of the thought being given at national level to the question of responsibility for situations of dependence and to legislative measures in this field;

Recalling the texts adopted within the Council of Europe also dealing with aspects of dependence, such as Recommendation No. R (87) 22 of the Committee of Ministers on the screening and surveillance of elderly persons, Recommendation No. R (90) 22 of the Committee of Ministers on the protection of the mental health of certain vulnerable groups of society, Recommendation No. R (91) 2 of the Committee of Ministers on social security for workers without professional status (helpers, persons at home with family responsibilities and voluntary workers) and Recommendation No. R (92) 6 of the Committee of Ministers on a coherent policy for people with disabilities;

Recalling Recommendation No. R (84) 24 of the Committee of Ministers on the contribution of social security to preventive measures;

Considering that a recommendation establishing a comprehensive and multidisciplinary approach towards assuming responsibility for the situation of dependence would be appropriate and that collective action at European level would foster better protection for dependent persons and their carers,

Recommends that the governments of member states:

- ensure public awareness of the problem of dependence as it is presented in this recommendation;
- orient policy measures in this field according to the principles set out below;
- ensure that their legislation takes account of the general principles and measures appended to this recommendation or, on introducing new legislation, adopt provisions conforming to these principles.

Appendix to Recommendation No. R (98) 9

1. Definition of dependence

Dependence is a state in which persons, by reason of lack or loss of physical, psychological or intellectual autonomy, require significant assistance or help in carrying out their usual day-to-day activities.

Dependence may afflict any section of the population and not only elderly people. Even though dependence tends to increase with age and is characterised in old age by the frequency of associated multiple health problems, age is not the only criterion of this state.

This draft recommendation does not deal with financial dependence.

2. General principles in respect of dependent persons

A policy for dependent persons or persons who may become dependent should aim:

- to prevent or reduce dependence, prevent it from increasing and alleviate its consequences;
- to help dependent persons to live life according to their own needs and wishes;
- to grant supplementary protection to dependent persons in the form of benefits or by facilitating access to existing services or by the creation of appropriate ones, such as family assistance services and access to appropriate technical aids.

All dependent persons or persons who may become dependent, regardless of their age, race and beliefs and the nature, origin and degree of severity of their condition, should be entitled to the assistance and help required to enable each of them to lead a life as far as possible commensurate with their ability and potential. They should therefore have access to services of good quality and to the most suitable technologies.

All dependent persons are entitled to respect for their human dignity and their autonomy. In this respect they should be involved in the evaluation of their degree of dependence and in any decisions concerning them.

This implies, *inter alia*, that all dependent persons must be informed of their rights, the possible choices and the resources available to them and the state of the relevant legislation.

At the same time, the public authorities have a duty to assume responsibility for dependence by adopting legislative measures in line with scientific and technological developments in this area in order to ensure equality of opportunity and guarantee access to care and services.

Public authorities should guarantee the quality of care and services.

Persons concerned by dependence must be treated without discrimination, particularly with regard to access to the infrastructure and services designed for them. Participation of dependent persons in social life, including leisure activities, should be encouraged, and access to such activities should be facilitated by the competent authorities.

3. Measures for dependent persons

Public authorities should pursue a coherent policy in co-operation with dependent persons, their carers and the organisations working in this field in order to ensure that they have the necessary assistance and help.

Implementation of the following measures implies co-ordination between the competent bodies. Public authorities should be responsible for the overall organisation of this co-ordination.

Member states should apply a system of benefits to which dependent persons would have an objective entitlement.

In addition to benefits, social protection systems should develop preventive measures, screening and early diagnosis of conditions that could lead to dependence.

3.1. Benefits

Benefits should be awarded and paid to persons living at home as well as to those living in institutions. However, home care should be encouraged.

Benefits should correspond to the different situations of dependent persons. They should be paid either in kind or in cash, directly or indirectly (reimbursement of costs incurred by the beneficiary).

Benefits should be awarded according to the degree of dependence. Dependence benefits are aiming at compensating additional financial charges brought about by loss of independence.

Benefits should be provided as long as a person needs care and assistance.

3.2. Freedom of choice

The freedom of choice principle is fundamental in guaranteeing respect for the dignity and self-determination of the dependent person. Freedom of choice may be realised within the legal framework of the social protection system.

To ensure that this principle is upheld, the choice must comprise two attributes: it must be free, which requires intervention by public authorities to give the persons concerned access to existing facilities and services and to promote other types of services adapted to the needs of dependent persons. In addition, the choice must be informed, which requires information that is accessible, objective, comprehensive and personalised.

Where freedom of choice is no longer possible due to the incapacity of the dependent person, legal protection should be instituted.

3.3. Prevention and rehabilitation

Prevention and rehabilitation are fundamental aspects of assuming responsibility for dependence.

Preventive action should be taken as early as possible to avoid the occurrence of dependence, to prevent it from worsening and to reduce the extent of dependence as much as possible.

Prevention should be on several levels:

- health education,
- accident prevention,
- detection and diagnosis,
- efficient treatment of causal diseases,
- reduction of the risk arising from isolation.

In addition, optimum rehabilitation must be encouraged given that dependence is not an absolute state but one which evolves, and that it exists in varying degrees. In this context, the principles set out in Recommendation No. R (92) 6 on a coherent policy for the rehabilitation of people with disabilities could be followed.

The principle of non-discrimination on the basis of age is crucial with regard to access to rehabilitation.

Rehabilitation should enable the dependent person to become as independent as possible in psychological, physical and social terms. Multidisciplinary intervention seems to be the best way to achieve this. The measures adopted must be adjusted to variations in the person's condition. It is essential to encourage ordinary activities and relationships.

Access to the necessary technical aids must be guaranteed.

3.4. *Assessing a dependent person's needs*

Assessment of a dependent person's needs should be based on the nature and the degree of dependence as determined through a multidisciplinary approach. The dependent person and/or those close to him or her should be able to contribute to assessing the person's needs.

Dependent persons should be entitled to reassessment of their condition and needs if dependence is increasing.

3.5. *Priority of home care*

Home care is generally preferred by the dependent person. It is an essential element in respect for the dignity and quality of life of the dependent person. Therefore freedom of choice also concerns the choice of residence.

The public authorities should make every effort to arrange for home care and include it as a priority in their policy for dependent persons through the adoption of relevant legislative provisions.

Making home care a priority means ensuring that a whole range of services is available to facilitate the life of dependent persons at home and that of their carers, thus :

- housing accommodation should be accessible and adaptable ;
- subsidies and/or tax exemptions should be granted to adapt existing housing.

A wide range of housing possibilities and of alternative forms of communal accommodation should be available. These should cover, *inter alia*, day centres and temporary accommodation in an establishment, but also alternative housing (for instance in collective therapeutic apartments).

Dependent persons living at home who need care, assistance and/or help should as far as possible be able to receive such help in their own homes.

All services should be complementary. Co-ordination between the hospital sector, the home-care sector and the social sector is necessary to enable dependent persons to remain at home and thus avoid or delay their institutionalisation.

Where institutionalisation is unavoidable, the rights of dependent persons must be safeguarded and their wishes taken into account.

3.6. *Guaranteeing the quality of care*

The type of care needed must be assessed with the person and those close to him or her. The choice should be based on the best solution for the particular needs of the dependent person concerned. Participation of the person concerned in the choice of care and in its planning process is an important tool to improve the quality of care. In order to achieve this, the team of advisors on care and the different care providers must receive training that is multidisciplinary and directed at the issue of dependence.

Co-operation and information exchange between the different protagonists are essential for ensuring continuity between the different care structures, an aspect that is vital for maintaining the dependent person's points of reference.

The role of the public authorities is to guarantee the quality of care (in particular by establishing a set of conditions and clearly defined evaluation rules). This involves monitoring the services provided and drawing up clearly defined quality standards.

Research

Measures to promote and co-ordinate basic and applied research in the field of dependence are necessary.

The results of this research should be distributed particularly to professionals and general practitioners.

Epidemiological studies carried out in accordance with a harmonised protocol enabling data from the different member states to be compared are also of primary importance. Results of research should be disseminated widely.

The pooling of national experience (pilot projects) should also be encouraged.

4. Carers without professional status

For the purposes of this recommendation, carers without professional status are family members, neighbours or other persons who care for and assist dependent persons and do not benefit from professional status conferring upon them the rights and duties associated with this status.

4.1. General principles applicable to carers without professional status

Assistance to dependent persons is a responsibility of society. It must be recognised as such by the public authorities, which have also a duty to take the necessary measures to improve the quality of life of carers, in particular by:

- recognising the importance and social value of the role of carers as key partners in the system of care and assistance for dependent persons;
- helping them to attain personal satisfaction in their work with dependent persons and total acceptance of their mutual roles, including respect for each party's independence;
- favouring the participation of carers in co-ordination with the multidisciplinary team so as to establish a specific network for each dependent person;
- making those close to carers aware of their shared responsibility for assisting dependent persons without discrimination on the basis of sex (this responsibility usually falling to women) and paying particular attention to young carers;
- allowing carers to benefit from respite measures.

The Committee of Ministers addressed the question of the social protection of carers without professional status in Recommendation No. R (91) 2. This recommendation forms an integral part of the present recommendation because its guiding principles can be applied to carers looking after dependent persons who should benefit from appropriate social protection.

4.2. Measures for carers without professional status

Training

Carers without professional status must receive suitable theoretical and practical training to ensure that the dependent persons' dignity is respected at all times and that appropriate steps are taken to protect their health, and preserve their autonomy and their physical and mental well-being.

The training must enable them to fulfil their duties to the optimum, including the provision of appropriate care. It should focus on the following aspects: basic principles of gerontology, psychology, ethics, communication with the dependent person and stress management. It should also include basic training in the provision of care (hygiene and ergonomics) and special training adapted to the specific case of the dependent person concerned (the use of technical aids, etc.).

The public authorities must encourage access to continuing training and retraining by developing opportunities for the temporary care of dependent persons.

Access to information

Carers must be informed of the state of legislation on the rights and assistance to which they are entitled. They must also be informed of all the possibilities available, including quality standards, codes of good practice, possibilities for support and relief, training, and so on.

Aid to carers and respite services

It is necessary to draw up support strategies for carers based on an understanding and recognition of their problems and needs. In particular, carers must be encouraged to take part in or form mutual assistance networks to give them the possibility of taking part in discussions and exchanges of experience and in material, psychological and social

support networks. These strategies should include improving their ability to deal with difficult situations, for example in cases of abuse and violence, where support networks are of special significance.

The right of carers without professional status to take leave is linked to the temporary care of dependent persons. The authorities must provide a sufficiently wide range of possibilities for respite (temporary care, whether institutional or other) to permit alternative care according to need.

Employment

In the case of carers without professional status who are also gainfully employed, consideration must also be given to adapting labour legislation in accordance with the principles set out in Recommendation No. R (96) 5 on reconciling work and family life. Similarly, provision should be made for the possibility of taking paid leave, in accordance with the rules governing maternity leave, in the event of a deterioration in the condition of an assisted dependent person.

Comprehensive support to enable those concerned to make the transition or return to employment after a period of assisting a dependent person should be envisaged.