

Recommendation CM/Rec(2010)2 of the Committee of Ministers to member states on deinstitutionalisation and community living of children with disabilities

(Adopted by the Committee of Ministers on 3 February 2010 at the 1076th 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 member states, *inter alia,* by promoting the adoption of common rules;

Recalling the Third Summit of Heads of State and Government of the Council of Europe (Warsaw, 16-17 May 2005) and the commitment to fully comply with the obligations of the United Nations Convention on the Rights of the Child, to effectively promote the rights of the child and to take specific action to eradicate all forms of violence against children, as well as the consolidation of the Council of Europe's work on disability issues and the support to its work on equity of access to care of appropriate quality and services which meet the needs of the population;

Taking into account the work of the Council of Europe in the field of childhood, family and disability policies and the following legal instruments:

- the Convention on Human Rights and Fundamental Freedoms (ETS No. 5), which protects the rights of everyone, including children;
- the revised European Social Charter (ETS No. 163), which guarantees, in particular, the right of persons with disabilities to independence, social integration and participation in the life of the community (Article 15); the right of the family to appropriate social, legal and economic protection (Article 16); the right of children and young persons to grow up in an environment that encourages the full development of their personality and of their physical and mental capacities (Article 17);
- the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (ETS No. 126);
- the European Convention on the Exercise of Children's Rights (ETS No. 160);
- the Convention on Contact concerning Children (ETS No. 192);

Bearing in mind Committee of Ministers' 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, which is designed to make decisive progress in ensuring equal rights for people with disabilities and promotes a human rights based, anti-discriminatory approach to improving the lives of all people with disabilities, including children and those with enduring and/or complex needs;

Recalling the Revised Strategy for Social Cohesion (2004), which gives particular attention to the groups at risk of becoming vulnerable and supports an inclusive approach, underlining the active reintegration of citizens and vulnerable groups;

Referring to the "Report of the High Level Task Force on Social Cohesion in the 21st century" (2007), which attaches a fundamental role to human rights as the cornerstone for cohesive societies along with human dignity and recognition, with particular attention to the interests of vulnerable or potentially vulnerable groups;

Recalling the "Building a Europe for and with children" 2009-2011 Strategy, which pursues and enhances the Council of Europe's commitment to children's rights and the eradication of violence against children, with special focus on particularly vulnerable children, without parental care and/or with disabilities;

Taking into account other resolutions and recommendations of the Committee of Ministers, notably:

- Resolution (77) 33 on placement of children, which stresses that placement should be avoided as far as possible through preventive measures of support to families in accordance with their special problems and needs;
- Recommendation No. R (79) 17 concerning the protection of children against ill-treatment;
- Recommendation No. R (84) 4 on parental responsibilities;
- Recommendation No. R (87) 6 on foster families;
- Recommendation No. R (94) 14 on coherent and integrated family policies;
- Recommendation No. R (98) 8 on children's participation in family and social life;
- Resolution ResAP(2005)1 on safeguarding adults and children with disabilities against abuse;
- Recommendation Rec(2005)5 on the rights of children living in residential institutions;
- Recommendation Rec(2006)19 on policy to support positive parenting, which asks public authorities to create the necessary conditions to implement a better reconciliation of family and working life through legal and other provisions, particularly for looking after children with disabilities as well as sick children;

Stressing the importance of the following United Nations conventions:

- Convention on the Rights of the Child (1989) to which all the member states of the Council of Europe are parties, and the basic principles of this convention should always underlie the upbringing of children;
- Convention on the Rights of Persons with Disabilities (2006) stressing the right of children with disabilities to be treated on an equal basis with other children, especially where they face additional disadvantages, including the right to express themselves on matters of concern to them, and the essential need for fully accessible services. States are urged to conduct public awareness campaigns that "nurture receptiveness" to the inclusion of disabled children and to collective responsibility for upholding their right to a life within the community;

Recalling Parliamentary Assembly recommendations, particularly Recommendation 1666 (2004) on "A Europewide ban on corporal punishment of children"; Recommendations 1601 (2003) on "Improving the lot of abandoned children in institutions" and 1698 (2005) on "The rights of children in institutions: follow-up to Recommendation 1601 (2003)";

Referring to the Declaration of the European Ministers responsible for Family Affairs at their 28th session (Lisbon, Portugal, 2006), which underlines the necessity to adopt programmes aimed at providing appropriate support for families with children with disabilities;

Bearing in mind that, as provided in the different international legal instruments of the Council of Europe, as well as in Article 3 of the United Nations Convention on the Rights of the Child, the best interests of the child shall be a primary consideration;

Recalling that children are persons with rights, including the right to be protected and to participate, to express their views, to be heard and be heeded;

Being aware of the fact that placing children in institutionalised forms of care raises serious concerns as to its compatibility with the exercise of children's rights;

Recognising the need for major changes in perceptions of people with disabilities and also for major changes to bring about non-discriminatory and inclusive practices;

Noting the need for a cross-sectoral and co-ordinated approach at all levels of government,

Recommends that the governments of member states take all appropriate legislative, administrative and other measures adhering to the principles set out in the appendix to this recommendation in order to replace institutional provision with community-based services within a reasonable timeframe and through a comprehensive approach.

Appendix to Recommendation CM/Rec(2010)2

I. General framework and basic principles

1. To succeed in promoting the deinstitutionalisation of children with disabilities and their life in the community, the following basic principles enshrined in international legal instruments should be taken into account:

1.1. all children have rights, hence disabled children have the same rights to family life, education, health, social care and vocational training as all children; long-term planning involving all stakeholders will be needed to ensure that children with disabilities are able to exercise the same rights as other children and to access social rights on the same basis as other children;

1.2. all disabled children should live with their own family, which is the natural environment for the growth and well-being of a child, unless there are exceptional circumstances which prevent this;

1.3. parents have the primary responsibility for the upbringing and development of the child; they should choose how to meet their child's needs as long as their decisions are informed by, and seen to be in, the child's best interests;

1.4. in all actions concerning children the best interests of the child take precedence over other considerations and this principle should be upheld in relation to children with disabilities;

1.5. if a family or a service fails to work in a disabled child's best interests, or if a disabled child is being abused or neglected, the state, acting through its public agencies and within general child protection frameworks, should intervene to protect the child and make sure that his or her needs are met; in these exceptional circumstances, if care is to be provided outside the family, such care should be welcoming, well regulated and designed to maintain family ties;

1.6. the state has a responsibility to support families so that they can bring up their disabled child at home and, in particular, to create the necessary conditions to implement a better reconciliation of family and working life: the state should therefore finance and make available a range of high-quality services from which the families of children with disabilities can choose assistance adapted to their needs.

II. Deinstitutionalisation and the transitional process at national level

2. Deinstitutionalisation requires a number of general actions to support the strategic approach at national level involving all stakeholders. Deinstitutionalisation being a long-term process, a well-planned and structured transition process is necessary. The planning should involve government representatives covering all policy areas that affect the lives of children with disabilities. The following are important aspects that should be taken into account:

2.1. a national, multidisciplinary system for identifying and assessing abilities and needs;

2.2. mutual support programmes for parents;

2.3. provision of various services (support for families, psychosocial support, financial support, educational support, pedagogical support, etc.);

2.4. appropriate consideration of the individual needs of children and their families;

2.5. availability of various measures to allow families to take a break and thus to prevent crises;

2.6. continuity of services and planning of periods of transition (childhood to adolescence, pre-school to school, school to adulthood);

2.7. promoting and supporting active involvement in, and ownership of, the situation by families.

3. Building of new institutions should be discouraged by refusing to approve and fund proposals for this type of project.

4. Public authority action, strategic planning and co-ordination at national, regional and local levels in the context of the deinstitutionalisation process should include the following four main strategies:

- a. the prevention of institutionalisation;
- b. the prevention of any prolongation of an initially foreseen short-term stay in an institution;
- c. the deinstitutionalisation of those who are currently in institutions;
- d. the creation of community-based services.

5. Deinstitutionalisation should be considered as an ongoing process that is constantly reviewed and there is a need to be vigilant in order to avoid returning to institutionalisation.

6. Transition from institutional to community-based services should be managed, anticipating resistance to change, challenging prejudices and removing barriers. During this period, services may be run in parallel.

7. While the transition is taking place, the commitment to children's rights applies equally to children who currently live in institutions, or in other types of care. Their successful social integration or reintegration should happen as soon as possible and their situation should be subject to periodic review with regard to the child's best interests; the child's parents should be supported as much as possible with a view to harmoniously reintegrating the child into the family and society.

8. Specific legislation mandating the authorities responsible for creating new networks of community-based care provision and setting a deadline at which point the admission of children to institutionalised forms of care will cease should be adopted. Where appropriate, links should be made to policies addressing poverty and the reduction of social exclusion. Measures taken to improve the governance of social services and non-governmental organisations (NGOs) working in the social care field should also be taken into account.

9. All new legislation, policy and guidance should be co-ordinated to ensure that they are applied equitably on behalf of disabled children, and that a commitment to disabled children is implicit in all legislation and government protocols. For this purpose, it would be relevant to appoint, or strengthen, the role of a children's ombudsman or commissioner. Where required, a timescale for legislative change with precise objectives and milestones against which progress can be monitored should be set up.

10. Organisations of parents and NGOs representing them should be included in the development of community-based services and their expertise should be used throughout the process of transition.

11. Funding should be allocated at national level and sought from international bodies, in order to facilitate and maintain the momentum of this process. Countries that experience difficulties should be able to ask the international community to share their knowledge on the subject or to ask them for other forms of support.

III. Alternatives to institutional forms of care

12. In exceptional cases (for example, where there has been abuse or neglect), when a child cannot live in his or her own family or a foster family, small, homely settings, that are as near to a family environment as possible, should be provided as an alternative to institutionalised forms of care.

IV. Actions as a prerequisite for the main strategies

13. Actions as a prerequisite for the main strategies are decisive for the success of the measures taken in a reform process and should:

13.1. assess each child's specific needs, on a regular basis, in order to design individualised programmes to ensure his or her social inclusion. Community-based services should respond to the needs identified;

13.2. assist those who may be in danger of being placed in an institution and find alternative solutions;

13.3. provide a strong legal base and quality standards for service provision; the quality of service provision should be regularly reviewed or assessed;

13.4. assess the existing services and the needs of all other stakeholders, such as service providers, families, etc.;

14. Adequate human and financial resourcing and continuing staff training as well as raising public awareness of the special needs of children with disabilities are equally important.

15. Funds should be allocated to research, monitoring and evaluation. An authoritative overview of the country's provision for children with disabilities and of those who remain in institutional settings, together with an audit of the community-based provision in place would be the first step in developing a research infrastructure. Aspects of community provision which need to be strengthened can be evaluated by mapping the needs of disabled children and their families and by learning about the pressures which lead families to seek placements away from home.

a. Prevention of institutionalisation

16. The creation of new institutions and new placements of children with disabilities in institutions should be prevented. For this reason, preventive measures of support for children and families in accordance with their special needs should be provided as early as possible.

17. Measures for the prevention of institutionalisation should include regular assessment and review of children's needs (once or twice a year), the establishment of individualised development plans and the implementation of quality standards for service provision.

b. Prevention of the prolongation of an initially anticipated short-term stay

18. Measures should be taken to avoid any unnecessary prolongation of an initially foreseen short-term stay in an institution. Short-term stays should remain exceptional, be adequately reviewed and should not lead to institutionalisation. In general, the measures for the prevention of institutionalisation are also applicable to this situation.

c. Deinstitutionalisation of those currently in institutions

19. Children have a right to regular reviews and reassessment of their placement in institutions so that they can be offered appropriate community services.

d. Creation of community-based services

20. A national action plan and a timetable should be drawn up to phase out institutional placements and replace these forms of care with a comprehensive network of community provision. Community-based services should be developed and integrated with other elements of comprehensive programmes to allow children with disabilities to live in the community.

21. An access mechanism should be put in place, in line with an assessment of needs, in order to direct families towards community-based provision and support.

22. Top priority should be given to funding and developing a range of community-based services for disabled children and their families with the aim of preventing children from being placed in institutions via:

22.1. timely and sensitive assessment of abilities and needs;

22.2. well co-ordinated health and social care;

22.3. early intervention programmes;

22.4. a range of options for mainstream and specialised education.

23. Some children with disabilities may need more intensive or more specialised service provision in order to meet their complex needs, but this should be seen as a spur to the development of high quality community-based support services and not as a barrier to their inclusion in ordinary settings.

24. A comprehensive family support system (including financial support to compensate for any additional costs incurred as a result of the child's disability, alongside a range of day-to-day support such as day care centres) should enable families to live a life which offers the same opportunities as families who do not have a disabled child. Services providing some respite and expert advice and counselling should be available for the disabled child's parents, siblings and carers, while at the same time offering developmental opportunities for the child.

V. Mainstreaming

25. Measures to uphold the interests of children with disabilities across all relevant policy domains should be taken. The interests and needs of children with disabilities should be addressed in the work of all ministries and other responsible bodies in line with the concept of mainstreaming or sector responsibility. At national level, there should also be coherent policies supporting the deinstitutionalisation approach across ministries (including in relation to workforce planning and support for training) in order to ensure that specialist expertise is developed, accredited and used appropriately. At regional or local government level, transparent policies for commissioning services on a statutory, voluntary or independent basis should be adopted.

26. Services for children with disabilities should be provided primarily in mainstream settings. Mainstreaming or sector responsibility should be viewed as the norm and not the exception. Agencies working with children should be helped to build their competence and capacity so that they can meet the needs of children with disabilities on an equitable basis.

27. The community should be involved and made aware of its responsibilities and obligations towards children with disabilities.

28. In future, mainstream services, including day care centres, pre-school set-ups, places of worship, schools and leisure services should be required to accept children with disabilities and make available the necessary support to aid their inclusion and participation. Wherever possible, children with disabilities should be educated – in all phases of their schooling – within the schools used by other children and receive the support required to facilitate their effective education or vocational training within the mainstream systems. Where special schools or units are deemed necessary or appropriate, these should be linked to ordinary schools, be helped to build bridges and be open to their local communities.

29. Likewise, health care should be provided by mainstream health-care professionals in ordinary clinics, surgeries and hospitals. When specialist interventions are needed, the preferred option should be for these to be made available locally. Assessments and expert consultations can often be carried out in the disabled children's normal environment, thereby cutting out the need for them to travel long distances and maximising the relevance of any advice offered.

30. One advantage of mainstreaming is that it allows children with disabilities to become more integrated into their local communities and to get to know other children, who in turn learn how to relate to them and see them as children first and foremost. Another advantage is that the care, services and support made available to children with disabilities can be evaluated using criteria that are relevant for all children.

31. All services should be designed and offered in ways that support family ties and foster good relationships between players, whether professional or not.

32. Mainstream professionals in education, health and social care services should receive additional training and assistance from local centres of excellence to equip them to work with children with disabilities, and to support their work with specific individual children. These services should incorporate a range of personalised support to assist disabled children so that they can aim for the same kind of life and aspirations as their peer group, as they are entitled to growing independence, autonomy, age-appropriate possessions, and assistive technology, especially with regard to mobility and communication, in accordance with their needs.

33. The principles of inclusion and universal design in relation to all public facilities designed for children and all publicly-funded housing and neighbourhood projects should be adopted. Transport systems in particular should be accessible to all children and adults. Co-ordination and quality in service provision should be ensured.

34. Mainstreaming or sector responsibility requires health, education and social care agencies to take children with disabilities into account in all their planning and service delivery from their inception.

VI. Co-ordination and quality in service provision

35. Some children with disabilities need intensive support in a number of domains: health or social care, educational development, technical assistance, psychological support, and help in decision making and in managing everyday life. They require assistance in building or sustaining social networks and in overcoming isolation or social exclusion. Expert co-ordination between professions and agencies should be foreseen, particularly for disabled children who need considerable support and constant assistance.

36. To achieve the right balance of general and expert assistance, centres of excellence, encouraging partnerships between service providers, NGOs, research and teaching institutes should be established and properly resourced in order to:

36.1. pool existing expertise on severe, complex or rare disorders and disabilities, including challenging needs;

36.2. support regular providers of education, health care and social care so that they can set up and implement specialised support programmes;

36.3. enhance work with multidisciplinary partners;

36.4. disseminate research and develop the evidence base for practice, through the work of national and international centres of excellence and university affiliated programmes;

36.5. provide, or facilitate, access to advice, information, counselling and multidisciplinary specialist healthcare services for children with disabilities, and their families.

37. At regional level, agencies and professions should work closely together. A special register should be kept to identify those children and families in need of support and this information should be standardised to allow information to be aggregated at regional and national level. This data should be stored in a format that allows it to be accessed in the context of international comparisons and research, subject to appropriate data protection protocols.

VII. Children with disabilities and their families as stakeholders in the process of service development

38. It is essential to change the way in which services to children with disabilities and their families are developed and provided by involving them in the process. Children with disabilities should have a say in the way that they are treated and, as they grow up, they should be allowed to shape their own future.

39. Young people with disabilities should increasingly be encouraged to make decisions for themselves and take control of their day-to-day lives. Close relatives should be involved in their own right, and they should be allowed to influence the development of the services they will be using.