

# Community Living and User Involvement: the Human Rights Context

by Angela Garabagiu, Council of Europe

## I. On the Human Rights Context:

*“We are all equal”*

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. People with disabilities 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. These frameworks are based on the universal respect for human rights and fundamental freedoms for all without distinction.

I would, of course, mention the opening for signatures on the 30<sup>th</sup> of March 2007 of the United Nations Integral International Convention on the Protection and the Promotion of the Rights and Dignity of Persons with Disabilities.

I shall, however, speak in greater detail about the Council of Europe Disability Action Plan 2006-2015, which we hope could become an operational instrument for the implementation of the Convention. I would simply recall the fact that this Action Plan was adopted by the Committee of Ministers on 5 April 2006, prior to the Convention, and that the negotiations at the Council of Europe proved extremely useful for the member states delegates that took part in the negotiations in New York.

### I.1. Council of Europe Disability Action Plan 2006-2015<sup>1</sup>

Member states will continue to work within anti-discriminatory and human rights frameworks to enhance independence, freedom of choice and the quality of life of people with disabilities and to raise awareness of disability as a part of human diversity.

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#### <sup>1</sup> **Brief History :**

In 1992, following the first European Conference of Ministers responsible for policies on people with disabilities (Paris 1991), the Recommendation No. R (92) 6 on a coherent policy for people with disabilities was adopted by the Committee of Ministers. This pioneering recommendation influenced disability policies for more than ten years and prompted new inclusive policy plans that have positively benefited people with disabilities both nationally and internationally.

However, major changes have taken place in society and new strategies were needed to further progress a social and human rights based approach to disability issues. In May 2003 at the Second European Ministerial Conference, which took place in Malaga, Spain, the Ministers responsible for policies on people with disabilities adopted the Malaga Ministerial Declaration on People with disabilities “Progressing towards full participation as citizens”, recommending the elaboration of a Council of Europe Disability Action Plan aimed at promoting human rights and improving of the quality of life of people with disabilities in Europe. In 2003, as a follow-up to the Malaga Ministerial Conference, the Committee of Experts on the Rehabilitation and Integration of People with Disabilities (Partial Agreement) (CD-P-RR) started the elaboration of the Council of Europe Disability Action Plan. Since the CD-P-RR acted in the framework of a Partial Agreement, the Committee decided to invite all the other Council of Europe member states to participate in the elaboration of the Disability Action Plan. The CD-P-RR also consulted 20 Council of Europe bodies and Steering Committees and 20 international disability NGOs. Moreover, for 3 consecutive meetings (2003-2005, CD-P-RR holds one meeting a year), funding was allocated from the Ordinary Budget to cover participation costs of non-Partial Agreement member states.

At the Third Summit (Warsaw, May 2005), the Heads of State and Government agreed to “consolidate the Council of Europe’s work on disability issues and support the adoption and implementation of a ten-year action plan designed to make decisive progress in ensuring equal rights for people with disabilities”.

Due account is taken of relevant existing European and international instruments, treaties and plans, particularly the developments in relation to the United Nations international convention on the rights of persons with disabilities.

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". The Recommendation is addressed to all 46 member states of the Council of Europe.

### **Essence**

The Council of Europe Disability Action Plan 2006-2015 seeks to translate the aims of the Council of Europe with regard to human rights, non-discrimination, equal opportunities, full citizenship and participation of people with disabilities into a European policy framework on disability for the next decade. It promotes the paradigm shift from a health-related to a social and human rights-based approach to disability: from the patient to the citizen.

The Action Plan is designed to be flexible to take account of future technological change and other developments<sup>2</sup>.

### **Key action lines**

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. For example, Disability Action Plan, in its Action Line 11 on Social protection brings the attention to a number of rights: "The social rights enshrined in the revised European Social Charter (ETS No. 163), include in particular the right to social security (Article 12), the right to social and medical assistance (Article 13), and the right to benefit from social welfare services (Article 14). The implementation of these rights helps to reduce the risk of social exclusion and marginalisation and hence contributes to opening access to another right enshrined in the Charter, namely the right of persons with disabilities to independence, social integration and participation in the life of the community (Article 15). "

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<sup>2</sup> Recent developments in the field of biotechnology and its potential use have created concerns amongst disabled people, to the point that even the right to life is sometimes in question. This plan deals with the full social inclusion and participation of disabled people and therefore it has not been considered appropriate to include such medically related issues as prenatal diagnosis and discrimination in abortion laws on the basis of disability. However, there is no doubt about the importance of these issues and it is considered vital to ensure that disabled people, through their representative organisations, participate in the relevant national and international ethics and bio-ethics committees dealing with these matters. (Rec(2006)5).

The Disability Action Plan refers to the human rights of particularly vulnerable groups of people with disability 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 Council of Europe Disability Action Plan 2006-2015 calls upon policy makers to initiate cross-cutting actions to ensure that individuals can reach their full potential, enjoy their rights and participate fully in society.

Let’s have a closer look at two groups:

Women and girls with disabilities often face multiple obstacles to participation in society due to discrimination on grounds of both gender and disability. The specific situation of women and girls needs to be taken into account in the development of both disability and gender mainstream policies and programmes at all levels.

Children with disabilities should enjoy the same rights – as laid down in the United Nations Convention on the Rights of the Child – and opportunities as other children. Young people with disabilities are also a vulnerable group in our society. They still face considerable barriers in accessing all aspects of life. The specific problems faced by children and young people with disabilities must be studied in greater depth in order to design and implement well informed policies across a wide spectrum of policy areas.

## **I.2 The example of the Right to Education**

**Let us take the example of the right to education:** the right to education for all has been incorporated in several instruments of the Council of Europe, the United Nations and the European Union.

Education is one of the main routes to personal development and self-fulfilment as well as to the labour market, self-support and integration into society. Effective efforts to include people with disabilities in the education system can prevent exclusion which they may otherwise experience later in life. All people with disabilities, regardless of the nature or degree of their disability<sup>3</sup>, have the right to appropriate free education adapted to meet their needs and wishes.

### **I.2.1 UN Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities**

#### **Article 24 - Education**

1. States Parties recognize the right of persons with disabilities to education. With a view to **realizing this right without discrimination and on the basis of equal opportunity**, States Parties shall ensure an inclusive education system at all levels and life long learning directed to:

- a. The **full development of human potential and sense of dignity and self-worth**, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
- b. The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
- c. Enabling persons with disabilities to participate effectively in a free society.

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<sup>3</sup> Article 1.1 of Chapter V. Education of the Appendix to the Recommendation No. R (92) 6 adopted by the Committee of Ministers on 9 April 1992 called “A coherent policy for the rehabilitation of people with disabilities”.

2. In realizing this right, States Parties shall ensure that:
- a. Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
  - b. Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
  - c. Reasonable accommodation of the individual's requirements is provided;
  - d. Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
  - e. Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community...

5. States Parties shall ensure that persons with disabilities are able to access **general tertiary education, vocational training, adult education and lifelong learning** without discrimination and on an equal basis with others. To this end, States Parties shall ensure that **reasonable accommodation** is provided to persons with disabilities.

### **I.2.2 European Convention for the Protection of Human Rights and Fundamental Freedoms**

Article 2 – “Right to education” of the Protocol to the European Convention for the Protection of Human Rights and Fundamental Freedoms (1952) states:

**“No person shall be denied the right of education.** In the exercise of any functions which it assumes in relation to education and to teaching, the State shall respect the right of parents to ensure such education and teaching in conformity with their own religious and philosophical convictions.” [emphasis added]

Article 14 – “Prohibition of discrimination” of the European Convention for the Protection of Human Rights and Fundamental Freedoms (1950) states:

“The enjoyment of the rights and freedoms set forth in this Convention shall be secured **without discrimination on any ground** such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with national minority, property, birth or other status.” [emphasis added]

### **I.2.3. European Social Charter**

The European Social Charter of 1961 is the counterpart to the European Convention on Human Rights in the field of economic and social rights. It sets out rights and freedoms and establishes a supervisory mechanism based on reports and collective complaints, guaranteeing their respect by the States Parties. The Revised European Social Charter of 1996, which came into force in 1999, is gradually replacing the initial 1961 treaty. The Charter and Revised Charter guarantee a wide range of rights relating to housing, health, education, employment, social protection, movement of persons and non-discrimination.

Article 15 – “Disabled people have the right to independence, social integration and participation in the life of the community” of the Revised European Social Charter (1996) states:

With a view to ensuring to people with disabilities, irrespective of age and the nature and origin of their disabilities, the effective exercise of the **right to independence, social integration and participation in the life of the community**, the Parties undertake, in particular:

- 1 to take the necessary measures to provide people with disabilities with guidance, **education** and vocational training in the framework of general schemes wherever possible or, where this is not possible, through specialised bodies, public or private;
- 2 to promote their access to employment through all measures tending to encourage employers to hire and keep in employment people with disabilities in the ordinary working environment and to adjust the working conditions to the needs of the disabled or, where this is not possible by reason of the disability, by arranging for or creating sheltered employment according to the level of disability. In certain cases, such measures may require recourse to specialised placement and support services;
- 3 to promote their full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure. [emphasis added]

Article 17 – “The right of children and young persons to social, legal and economic protection” of the Revised European Social Charter (1996) states:

With a view to ensuring the effective exercise of the right of children and young persons to grow up in an environment which encourages the full development of their personality and of their physical and mental capacities, the Parties undertake, either directly or in co-operation with public and private organisations, to take all appropriate and necessary measures designed:

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  - a to ensure that children and young persons, taking account of the rights and duties of their parents, have the care, the assistance, the **education** and the training they need, in particular by providing for the establishment or maintenance of institutions and services sufficient and adequate for this purpose;
  - b to protect children and young persons against negligence, violence or exploitation;
  - c to provide protection and special aid from the state for children and young persons temporarily or definitively deprived of their family’s support;
- 2 to provide to children and young persons a **free primary and secondary education** as well as to encourage regular attendance at schools. [emphasis added]

Article E – Non-discrimination of Part V of the Revised European Social Charter (1996) states:

The enjoyment of the rights and freedoms set forth in this Charter shall be secured **without discrimination on any ground** such as race, colour, sex, language, religion, political or other opinion, national extraction or social origin, health, association with a national minority, birth or other status. [emphasis added]

### **I.2.3.i The control mechanisms of the ECS: European Committee of Social Rights**

The European Committee of Social Rights (referred to below as “the Committee”) ascertains whether countries have honoured the undertakings set out in the Charter. Its thirteen independent, impartial members are elected by the Council of Europe Committee of Ministers for a period of six years, renewable once. The Committee decides whether or not national law and practice in the States Parties are in conformity with the Charter and Revised Charter.

### **I.2.3.ii The control mechanisms of the ECS: A monitoring procedure based on national reports**

Every year the States Parties submit a report indicating how they implement the Charter in law and in practice. Each report concerns some of the accepted provisions of the Charter or Revised Charter. The Committee examines the reports and decides whether or not the situations in the countries concerned are in conformity with the Charter or Revised Charter. Its

decisions, known as “conclusions”, are published every year. If a state takes no action on a Committee decision to the effect that it does not comply with the Charter or Revised Charter, the Committee of Ministers may address a recommendation to that state, asking it to change the situation in law or in practice. The Committee of Ministers’ decisions are prepared by a Governmental Committee comprising representatives of the governments of the States Parties to the Charter and Revised Charter, assisted by observers representing European employers’ organisations and trade unions.

### **I.2.3.iii The control mechanisms of the ECS: A collective complaints procedure**

Under Protocol 3, opened for signature in 1995, entered into force in 1998, complaints of violations of the Charter and Revised Charter may be lodged with the European Committee of Social Rights by organisations entitled to lodge complaints with the Committee.

*In the case of all states that have accepted the procedure:*

1. the European Trade Union Confederation (ETUC), the Union of Industrial and Employers’ Confederations of Europe (UNICE) and the International Organisation of Employers;
2. Non-governmental organisations (NGOs) with consultative status with the Council of Europe which are on a list drawn up for this purpose by the Governmental Committee;
3. Employers’ organisations and trade unions in the country concerned;

*In the case of states which have also agreed to this:*

4. National NGOs.

The Committee examines the complaint and, if the formal requirements have been met, declares it admissible. Once the complaint has been declared admissible, a written procedure is set in motion, with an exchange of memorials between the parties. The Committee may decide to hold a public hearing. The Committee then takes a decision on the merits of the complaint, which it forwards to the parties concerned and the Committee of Ministers in a report, which is made public within four months of its being forwarded. Finally, the Committee of Ministers adopts a resolution. If appropriate, it may recommend that the state concerned takes specific measures to bring the situation into conformity with the Charter or the Revised Charter.

The first collective complaint concerning Article 15 is Complaint No 13/2002 **Autisme Europe v France**. This complaint lodged in July 2002 relates to Article 15 § 1, Article 17§ 1 (right of children and young persons social, legal and economic protection and includes the right to education) and to Article E (non-discrimination) of the Revised Charter. It alleges insufficient educational provision for persons with autism constituting a violation of the above- mentioned provisions. The Committee declared the complaint admissible in December 2002 and delivered its decision on the merits in November 2003. The Committee concluded that the situation constitutes a violation of Articles 15 § 1 and 17 §1 whether alone or read in combination with Article E. This decision was followed by the adoption of Resolution Res Chs (2004) 1 in March 2004.

## **I.2.4. Education-related aspects of the Council of Europe Disability Action Plan 2006-2015**

### **I.2.4.i Action Line 4. Education**

The Action Plan clearly states that education is a basic factor in ensuring social inclusion and independence for all people, including those with disabilities. This key Action Line addresses education in all stages of life, including pre-school, primary, secondary, higher education[1] and professional training, as well as life-long learning. The creation of opportunities for disabled people to participate in mainstream education is not only important for disabled people but will also benefit non-disabled people’s understanding of human diversity.

The Action Plan identifies four specific objectives, that member states will aim at achieving in the next decade: i) ensuring that all persons, irrespective of the nature and degree of their impairment, have equal access to education, and develop their personality, talents, creativity and their intellectual and physical abilities to their full potential; ii) ensuring that disabled people have the opportunity to seek a place in mainstream education by encouraging relevant authorities to develop educational provision to meet the needs of their disabled population; iii) supporting and promoting lifelong learning for disabled people of all ages and facilitating efficient and effective transitions between each phase of their education and between education and employment; and iv) fostering at all levels of the educational system, including in all children from an early age, an attitude of respect for the rights of people with disabilities.

#### **I.2.4.ii Specific actions by member states**

A number of specific actions are suggested. Some are directly addressed to policy makers: *“...To promote legislation, policies and planning to prevent discrimination against children, young people and adults with disabilities in the access to all phases of their education from early years through to adult provision. In doing so, consult with disabled users, parents, and carers, voluntary organisations, and other relevant professional bodies, if appropriate”*.

Others are addressing care-givers, researchers, and administrators in education: *“to enable the early appropriate assessment of the special educational needs of disabled children, young people and adults to inform their educational provision and planning”*;

Next actions could require the special attention of pedagogues, and curriculum developers: *“to monitor the implementation of individual education plans and facilitate a co-ordinated approach to education provision throughout and towards employment[1]”*; and *“to include, in school civic education syllabuses, subjects relating to people with disabilities as people who have the same rights as all other citizens”*;

And, finally, some require taking note of the non-formal education or other specific arrangements that contribute to the advancement of the education of a person with disabilities: *“to ensure access to non-formal education allowing disabled youth to develop needed skills otherwise unattainable through formal education”*.

*It is important to set priorities for action. Co-operation with other international organisations could also be envisaged (e.g. UNESCO Salamanca Statement and Framework for Action on Special Needs Education (1994); and the UN Disability Convention (2006).*

#### **I.2.4.iii Relevant cross-cutting aspects**

*Children and young people with disabilities:* The Convention on the Rights of the Child is based on a number of principles, such as the child’s right to not be discriminated against; and the child’s right to life and development. Boys and girls with disabilities also have the right to access these same rights. The needs of children with disabilities and their families must be carefully assessed by responsible authorities with a view to providing measures of support which enable children to grow up with their families, to be included in the community and local children’s life and activities. Children with disabilities need to receive education to enrich their lives and enable them to reach their maximum potential[1].

*People with disabilities from minorities and migrant communities:* People with disabilities from minority groups, disabled migrants and refugees may experience multiple disadvantages because of discrimination or lack of familiarity with public services. As an example, despite increased attention paid to Roma in Europe, further action is needed to recognise their status as full and equal members of society. Inside their own community, disabled people are considered as invisible and are therefore a specifically vulnerable group. Education, together with the employment, social health services and cultural life, is a particularly important area to be addressed.

#### **I.2.4.iv Application in the field of education of some specific principles addressed by the Disability Action Plan**

### *Universal Design*

Equality of access is essential for the development of a fully inclusive society. The design of buildings, the environment, products, communication and electronic systems is particularly important to facilitate the participation and independence of people with disabilities in all aspects of life. Universal Design is an effective way to improve the accessibility. It focuses on the importance of ensuring that design is right from the start. In the field of education this translates into measures to ensure accessibility of schools or other educational establishments, as well as the accessibility of educational materials.

### *Quality of services and training of staff*

Quality and training are key principles which underpin the action lines in this Plan. This not only includes appropriate training for the personnel involved in service delivery, both disability specific and mainstream services, but also for those who have a role in developing policies which affect the lives of people with disabilities. Training should incorporate awareness of the human rights of people with disabilities. This is particularly important for the re-training of teachers and administrative personnel in educational establishments (schools, universities, technical colleges, etc.). The Disability Action Plan clearly recommends *“to encourage the development of initial and ongoing training for all professionals and staff working across all phases of education to incorporate disability awareness and the use of appropriate educational techniques and materials to support disabled pupils and students where appropriate”*.

## **II. On User Involvement:**

*“Therefore we all have to have a say on what concerns us”*

“In general, independence for the person with a disability means acquiring as great a degree of self-reliance as possible, and this can be achieved through rehabilitation. In order to be as independent as possible and no longer play a secondary role in society, the person with a disability should take an active part in his or her own rehabilitation. Independence is a trend which seems ever more apparent at all stages of the rehabilitation process. There is a transition from a rehabilitation system in an institution, based on the *dependence* of the person with a disability, to a system where the emphasis is placed on giving the person the greatest possible *independence* and which arises from the full recognition of the right to be different. It is the duty of society to adapt itself to the particular needs of people with disabilities.

Integration demands that the general public, teachers, the social partners, and others, particularly the family of the person with a disability, play an increasingly important part in backing up those efforts made by the person with a disability. The role of the family is particularly important and appropriate aid should be made available to every family caring for a person with a disability.”(Recommendation No. R (92) 6 of the Committee of Ministers to member states on a Coherent Policy for people with disabilities).

### **II.1 Accent on user involvement in the Council of Europe Disability Action Plan 2006-2015**

The Action Plan 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.

#### **II.1.1 Example 1: Action line No.1: Participation in political and public life**

##### *Objectives*

“iv. to ensure that people with disabilities and their representative organisations are consulted and have a role to play in determining policies for people with disabilities.”

##### *Specific actions by member states*

- i. To ensure that voting procedures and facilities are appropriate and accessible to people with disabilities so that they are able to exercise their democratic rights, and allow, where necessary, the provision of assistance in voting;...
- iii. to ensure that no person with a disability is excluded from the right to vote or to stand for election on the basis of her/his disability;
- iv. to ensure that election information is available and accessible in all necessary alternative formats, and easy to understand;...
- vii. to encourage consultation with people with disabilities and their organisations on an equal basis to others, in the democratic decision-making process;

### **II.1.2 Example 2: Action line No. 2: Participation in cultural life**

#### *Introduction*

The right of people with disabilities as individuals to be fully integrated into society is dependent on them being able to participate in the cultural life of that society. If people with disabilities are to remain or become independent they must have as complete a life as possible interacting with other members of society, be they disabled or non-disabled people. They have the right to participate in culture, leisure, sport and tourism.

The Council of Europe and its member states are committed to taking the rights of people with disabilities into account when formulating and implementing their cultural policy. Concerted action is required to transform the opportunities and quality of life for people with disabilities through their access and involvement in the arts and social life.

#### *Specific actions by member states...*

- iii. to encourage their broadcasting and related creative industries to ensure that people with disabilities can access broadcasting, films, theatre plays and other arts-related activities in accessible formats which may include captioning, subcript, audio description and sign language;...
- vi. to enable people with disabilities to enjoy access to culture, sports, tourism and leisure activities by, for example, encouraging providers to make their premises and services accessible through whatever means that are necessary;

### **II.1.3 Example 3: Action line No. 11: Social protection**

#### *Objectives*

- i. To provide equal access to social protection for people with disabilities;
- ii. to promote policies which progress the shift from financial benefit dependency towards, where possible, employment and independence.

#### *Specific actions by member states*

- i. To ensure a coherent balance between social protection measures and active employment oriented policies in order to discourage inactive benefit dependency;...
- iii. to ensure that all benefit assessment systems and procedures are accessible to people with disabilities or their representatives;...
- vi. to consult with social partners and other key actors, including organisations of people with disabilities, in relation to the planning and implementation of social protection policies;

## **III. On Community Living (de-institutionalisation):**

*“In practical terms, make sure that we are part of the society enjoying same services as anyone else”*

### **III.1 The Committee of Experts on Community Living (De-institutionalisation) of Children with Disabilities (P-RR-CLCD) works considering that:**

“De-institutionalisation is a long term process which requires government action, strategic planning and coordination at national, regional and local levels. Initially it may be necessary to run services in parallel, so that a range of high quality, properly regulated community-based options can be built up alongside a *gradual* disinvestment in large scale services. The rights

of disabled children and vulnerable young adults who remain in institutional services should be assured throughout this process.

Institutions are often large scale, segregated settings, in which children have little or no contact with their families or communities. [...]

Community services take many forms. A broad range of mainstream and specialist service provision, supporting the integration of children with disabilities, is discussed below.”

**III.2 Excerpt of the St Petersburg Declaration** (Final Declaration of the European Conference on “Improving the quality of life of people with disabilities in Europe: participation for all, innovation, effectiveness”, St. Petersburg, Russian Federation, 22 September 2006 (ED CONF(2006)4 final):

“Recommends that countries move gradually but purposefully towards de-institutionalisation, with an urgent focus on the needs of children, and take steps to facilitate the inclusion of all disabled children and adults in mainstream service provision and in valued roles within their communities through universal design and participation in activities that enhance their visibility and status, such as their involvement in the arts, music, culture and politics, and in sports [...]”.

**III.3 Action Line No. 8: Community living of the Council of Europe Disability Action Plan 2006-2015**

*3.8.1. Introduction*

This action line focuses on enabling people with disabilities to live as independently as possible, empowering them to make choices on how and where they live. This requires strategic policies which support the move from institutional care to community-based settings ranging from independent living arrangements to small group homes. Such policies should be flexible, covering programmes which enable persons with disabilities to live with their families and recognising the specific needs of individuals with disabilities requiring a high level of support.

In general, a family’s day-to-day life differs considerably depending whether or not it has a child with a disability: guidance and care, for instance, take up a great deal of time, visits to therapists, doctors, etc., are necessary, the child needs supervision in recreational activities and assistance with the practical aspects of daily living, etc. It is important that parents of children with disabilities can have access to suitable training enabling them to acquire the requisite proficiencies to lead a life as close as possible to normal with their disabled child.

Full independent living may not be a possibility or a choice for all individuals. In exceptional cases, care in small, quality structures should be encouraged as an alternative to living in an institution. The design of independent living arrangements should involve people with disabilities and their representative organisations.

Disabled people living in the community have different needs that require different levels of care, assistance and support. Transparent eligibility criteria and independent individual assessment procedures, which take into account disabled persons’ own choice, autonomy and welfare, will promote equitable access to services.

Independent living policies are not just confined to living arrangements, but are also dependent on the accessibility of a broad range of services, including transport. The success of such policies requires a mainstream approach to the planning, development and delivery of mainstream services to ensure they also respond to the needs of individuals with disabilities with cross-agency support to ensure a co-ordinated approach.

*3.8.2. Objectives*

- i. To enable people with disabilities to plan their life and live as independently as possible in their community;

ii. to provide a broad range of quality support services at community level in order to allow for freedom of choice;

iii. to pay special attention to the situation of families that have a child/children with disabilities and advocate an approach that accommodates training for parents concerned, as well as to disabled parents and their participation in child-care and education tasks.

#### 3.8.3. *Specific actions by member states*

i. To ensure a co-ordinated approach in the provision of community-based quality support services to enable people with disabilities to live in their communities and enhance their quality of life;

ii. to develop and promote housing policies which enable people with disabilities to live in suitable housing in their local community;

iii. to support formal and informal help, making it possible for people with disabilities to live at home;

iv. to recognise the status of carers, by providing them with support and relevant training;

v. to have the needs of families as providers of informal care thoroughly assessed, especially those with children with disabilities or caring for persons in need of a high level of support, with a view to providing information, training and assistance, including psychological support, to enable life within the family, paying particular attention to the reconciliation of private and professional life and to gender equality;

vi. to ensure community-based quality service provision and alternative housing models, which enable a move from institution-based care to community living;

vii. to ensure that individuals can make informed choices with the assistance, when appropriate, of a skilled advocacy service;

viii. to promote schemes which will allow disabled people to employ personal assistants of their choice;

ix. to provide complementary services and other facilities, for example day centres, short-stay centres or self-expression groups, offering suitable forms of therapy, to give people with disabilities and their families periods of support and respite;

x. to provide people with disabilities, in particular those in need of a high level of support, with tailored support provision, including advocacy, in order to reduce any risk of social exclusion;

xi. to implement the relevant provisions included in Recommendation No. R (96) 5 of the Committee of Ministers to member states on reconciling work and family life.”

#### **IV. Closing: Implementation of the Council of Europe Disability Action Plan 2006-2015 – member states’ responsibility**

*“All other areas of life must be developed so that to improve the quality of life of people with disabilities and to promote their full participation as citizens.*

The Disability Action Plan acknowledges the basic principle that society has a duty towards all its citizens to ensure that the effects of disability are minimised through actively supporting healthy lifestyles, safer environments, adequate health care, rehabilitation and supportive communities.

The key objective of the Disability Action Plan is to serve as a practical tool to develop and implement viable strategies to bring about full participation of people with disabilities in society and ultimately mainstreaming disability throughout all the policy areas of the member states.

The Action Plan aims at meeting country-specific conditions as well as transition processes that are taking place in various member states.

It comprises recommendations to take specific actions at national level and also illuminates aspects of vulnerable groups of people with disabilities who face specific barriers and problems that require a cross-cutting response. It encourages member states to respond to the needs of people with disabilities by providing quality and innovative services and consolidating measures already in place.

The implementation is the responsibility of member states. The Plan itself and the Committee of Ministers emphasised the importance of establishing partnerships with non-governmental organisations of people with disabilities in the implementation and follow-up of the Disability Action Plan.

The Terms of Reference of the European Co-ordination Forum for the Council of Europe Disability Action Plan 2006-2015 (CAHPAH) were adopted by the Committee of Ministers at its 973<sup>rd</sup> meeting on 13 September 2006, and its first meeting will take place in Strasbourg on 26-27 April 2007.