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Ad Hoc Group of Experts on Community Living (Deinstitutionalisation) of children with disabilities
(P-RR-CLCD)

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Final report:

Service provision for children with disabilities and their families in 28 European countries

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Service provision for children with disabilities and their families in 28 European countries

A snapshot of the current situation

Draft-report based on the findings from a questionnaire,
circulated to the member states of the Council of Europe

February 2006

Dr Klaas Gorter

Contents

1. Introduction

Within the conceptual framework of the Council of Europe's 'Strategy for Social Cohesion' and forthcoming 'Action Plan to promote the rights and full participation of people with disabilities on society: improving the quality of life of people with disabilities' a committee was established to be engaged in issues concerning children with disabilities. This 'Ad Hoc Group of Experts on Community living (Deinstitutionalisation) of Children with Disabilities' (P-RR-CLCD) had its first meeting in June 2005. The purpose of the P-RR-CLCD is to make recommendations and establish guidelines which will lead to the de-institutionalisation of children with disabilities, promotes the policy of community living and supports families who care for their disabled children within their home.

1.1 Collecting data in the Council of Europe's member states

In order to undertake an initial stocktaking of national policies towards children with disabilities in the Council of Europe member states, it was decided to circulate a questionnaire to the states. The aim of this questionnaire is to gather information on existing national policies and services to meet the needs of children with disabilities and their families.

In its first meeting the P-RR-CLCD agreed on the topics which should be included in the questionnaire. The questionnaire was completed after members of the Group gave their comments on a first draft.

It contains the following questions:

Baseline data about the population

Q1 Population below 18 years
  Q1a What is the population of children between 0 and 18 years in your country?
  Q1b What is the population of children with disabilities between 0 and 18 years in your country?

Q2 Nature of disability
  Q2a Please give the definition of disability generally used in your country when providing services for disabled children.
  Q2b Under the definition of disability that you use do you treat children as disabled when they have a:
    a) physical impairment?
    b) sensory (seeing, hearing) impairment?
    c) intellectual/learning impairment?
    d) mental (psychiatric) disorder?
    e) other condition (Please give details of the other conditions that you treat as being a disability.)

Q3 Type of data held
  Q3 Does the data you record about the children with disabilities include information about:
    a) age?
    b) gender?
    c) type of disability?
    d) kind(s) of support they receive?
    e) living in long- term residential placements?
    f) in receipt of community-based services?

g) other information? (Please give details of the other information you collect about disabled children.)

Policy

Q4 Aims and scope of key policies

- Q4a Please summarise the key policies being implemented in your country to support the development of services for children with disabilities.
- Q4b If the policies detailed in answer to Q4a include measures aimed at changing provision from a system of mainly residential provision to community based provision, please give brief details on the specific areas you would like to identify as examples of good practice?

Q5 The role of government at different levels: What are the roles of the central government, regional government and local authorities in developing and improving services for children with disabilities?

Q6 Consultation

- Q6a Do you consult with disabled children and/or their families when developing policies that concern them?
- Q6b Do you consult with disability and/or children's organisations?
- Q6c If yes: Briefly describe the methods of consultation you use.

Services and their users

Q7 Services available for children with disabilities

Explanation: Please give brief details of the major services for children with disabilities including, education, housing, health-related long-term care, social care and transport. Do not include acute medical care (from general practitioners, hospitals and the like).

For each major service-providing organisation in your country please give a brief description of:

- a) The service/s provided and its target group.
- b) What proportion of each of the major services is delivered to disabled children by mainstream provision / specialist provision.
- c) What proportion of each major service is delivered through residential placements?
- d) What proportion of these services is provided by either central government, local government, private organisations, voluntary organisations or charities.
- e) Number of users (children with disabilities)

Q8 Services the parents: What support is available to families with a disabled child in your country?

- a) information about service provision options available
- b) help with finding and accessing services
- c) benefits/grants to meet additional costs of having a child with a disability
- d) other type/s of support (Please specify)

Q9 Funding: How are services for children with disabilities funded in your country?

In July the secretariat of the P-RR-CLCD submitted the questionnaire to all member states. They were asked to respond by October 10.

1.2 Response

In total 30 countries have returned the questionnaire. In alphabetic order: Albania, Andorra, Austria, Belgium (3: from both the Flemish, Walloon and German speaking regions), Bulgaria, Croatia, Cyprus, Czech Republic, Estonia, Finland, France, Georgia, Germany, Ireland, Italy, Latvia, Liechtenstein, Luxembourg, Moldova, Netherlands, Norway, Portugal, San Marino, Serbia & Montenegro, Spain, Sweden, Turkey and the United Kingdom (2: from England and Scotland). Thus the response rate amounts to 61% (28 out of the 46 member states of the Council of Europe).
Next to these countries, we received data from two observer states to the Council of Europe: Japan and Mexico.

1.3 The report

In the next sections the findings from the 28 European countries are presented.
At first we describe the definitions of disability and state the numbers of children with disabilities in the participating countries.
In the subsequent sections the main themes are considered: the various systems of service provision for disabled children (section 3) and the policies concerning disabled children (section 4).
In section 5 we suggest a framework for drawing recommendations.
The report ends with some conclusions.

As outlined in the contract, the report should be concise, preferably not exceeding 20 pages. However, it turned out that we needed some more pages to present the data. For the full text of the replies to the questionnaire from each of the participating countries the reader is referred to the "Compilation".

2. Definitions of disability and number of disabled children

2.1 Definitions

The respondents were asked to 'give the definition of disability generally used in your country when providing services for disabled children'.

Although most cited definitions have much in common, also marked differences appear. We review some characteristics.

Impairments and limitations

In many definitions disabled persons are described as:

- having an *impairment*[1] in bodily or mental structures or functions,
- that produces *limitations in functioning and social participation*.

An example is the definition of the rehabilitation law in province of Tyrol (Austria): "A disabled person is a person who for the reason of physical or psychological suffering or weakness is permanently and substantially *reduced in his/her ability to live an independent live within the society"*.
In Serbia & Montenegro: "The term disability summarises a great number of different functional limitations. Under the definition of disability in Serbia and Montenegro are: physical, intellectual, sensory and mental impairment. The term 'person with disabilities' means *limitation of opportunities to take part in the life on equal level with others*".

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[1] This and other italics in the text are added by the author of this report.

And in Portugal: " A person with disabilities is a person who, on account of a loss, congenital or acquired anomaly of the body functions or structures, including the psychological functions, has specific difficulties in the interaction with environments factors resulting in activity limitations and participation restrictions, compared to other people”.

Long-term conditions

Several definitions explicitly add that the condition should be *long-term*. For instance Finland: "A disabled person means a person who, because of his/ her disability or illness, has special *long-term difficulties* in managing the normal functions of everyday life". And the Flemish Fund in Belgium defines disability as "a *long-lasting* and substantial limitation of the possibilities of social integration due to reduced intellectual, psychological, physical or sensory capacities".
In some countries a minimum duration is stated, like the Czech Republic (at least one year) and Germany (at least 6 months).

Substantial effects

The quality '*substantial'* in the Flemish definition is also found in some other definitions. For instance the Scottish definition states that "A person has a disability if he has a physical or mental impairment which has a *substantial* and long term adverse affect on his ability to carry out normal day-to-day activities". The Swedish Act on Support and Service for Persons with Certain Impairments refers to "physical or mental functional impairments which are manifestly not due to normal ageing, if these impairments are *major* ones and cause *considerable* difficulties in daily life and, consequently, an extensive need for support and service.

The English definition (in the Disability Discrimination Act) covers all three features mentioned above: "A person has a disability if he or she has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day to day activities".
In France a similar definition exists: "A disability is any limitation of a person's activity or restriction of their participation in life in society, experienced in the person's environment because of a substantial, lasting or permanent alteration of one or more physical, sensory, mental, cognitive or psychological functions, a multiple disability or an incapacitating health disorder".

Need for support

The *need for support* is stated in some other definitions as well. In Estonia: "Disability is loss or disorder of an anatomical, physical or psychic structure or function, which requires that the person *needs external help, guidance or surveillance*". And in Belgium (Walloon region) a disabled person is defined as "any adult or minor with a significant impairment of his/her capacities for social or employment integration following a deterioration in mental, sensory or physical faculties which result in the *need for society to intervene*".

In some countries the term 'social protection' is employed, for instance Georgia: "Disability is an impairment of human health caused by a disease, trauma, anatomical or mental defect, accompanied by a substantial restriction of body functions, which results in temporary or permanent limitation of life activities and requires of person’s social protection". And Turkey: "A disabled is a person who has difficulties in adaptation to social life and daily necessities and needs protection, care, rehabilitation, counselling and assistance services, because of loss of physical, mental, psychological, sensory and social abilities in various levels congenitally or subsequently".

Denoting specific diseases

The laws in some countries specify certain conditions or diseases. This applies to the Walloon region in Belgium, Croatia and Moldova. Conditions are denoted in medical terms, like mental disorders, impairment of the central nerve system, impairment of organs and organ systems, cerebral palsy, eye diseases, respiratory disorders, epilepsy etc.

In England a restriction is made: *progressive* conditions, *leading to impairment*. Relevant examples are cancer, multiple sclerosis, muscular dystrophy and HIV infection. Furthermore, the English concept identifies severe disfigurements.

Including environmental factors

Finally, we point to a distinguishing attribute of some definitions. The Norwegian definition is formulated as follows: "People with reduced functional ability do not automatically become disabled. A person is disabled when there is a *gap between the individual's capabilities and the way in which society is formed or the functions required by society*". This statement is in agreement with the International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organization. The ICF differs from its former version (the International Classification of Impairments, Disabilities and Handicaps, ICIDH) in several respects. An important one is the inclusion of *environmental factors*. The idea behind this addition is that an individual's functioning always occurs in a context. It is recognition of the importance of the role of environmental factors in either facilitating functioning or creating barriers for people with disabilities. The Standard Rules on the Equalization of Opportunities for Persons with Disabilities, drafted by the United Nations, also calls attention for the environment by stating: "The terms 'disability' and 'handicaps' were often used in an unclear and confusing way, which gave poor guidance for policy making and for political action. The terminology reflected a medical and diagnostic approach, which ignored the imperfections and deficiencies of the surrounding society. Shortcomings in the environment prevent persons with disabilities from participation on equal terms". In Luxembourg, the definition shows a similar approach: "Disability is a function of the relationship the disabled persons have with their environment. It arises when such persons encounter material, social or cultural obstacles that prevent them from accessing various societal systems available to their fellow citizens. Disability is therefore the loss or limitation of the possibility of taking part in the life of the community on an equal footing."

Including and excluding types of impairments

After stating their definition, respondents were asked (Q2b) to indicate whether children are treated as disabled when they have a
(a) physical impairment,
(b) sensory (seeing, hearing) impairment,
(c) intellectual / learning impairment,
(d) mental (psychiatric) disorder,
(e) other condition.

Results show that in most states the term 'disability' applies to all types of impairments and disorders, both physical, sensory, intellectual and mental. However, about mental (psychiatric) disorders is less consensus. In some countries (Italy, Netherlands and German speaking region of Belgium), persons with mental disorders are not labelled as disabled. Among the specified other conditions (e) chronic / long-term / internal diseases is the most frequent category. Some others mentioned autism and behavioural problems. Reduced working capacity is also mentioned, but this condition is only applicable for older children.

2.2 Number of disabled children

The respondents were asked to state (Q1a) the total number of children between 0 and 18 years in their country and (Q1b) the (estimated) number of children with disabilities in this age category. From this figures the prevalence of disability among the children can be calculated, provided that the estimation includes all disabled children. The findings are presented in the following table.

Number of children between 0 and 18 years

Country	**Total (Nx1000)**	**With disabilities* (Nx1000)**	**% with disabilities (calculated)**
Albania	1,396	4	0.3
Andorra	15	0.1	0.8
Austria	1,815	64	3.5
Belgium (Fl.)	1,342	43	3.2
Belgium (Wall.)	829	-	7.0
Belgium (Germ.)	16	0.2	1.0
Bulgaria	1,488	21	1.4
Croatia	1,033	15	1.4
Cyprus	152	2	1.5
Czech Republic	2,184	-	-
Estonia	281	6	2.2
Finland	1,168	39	3.3
France	6,965	240	3.4
Georgia	1,137	11	0.9
Germany	15,237	164	1.1
Ireland	900	15	1.7
Italy	11,000	200	1.8
Latvia	460	9	2.0
Liechtenstein	7	-	
Luxembourg	106	2	1.5
Moldova	714	13	1.9
Netherlands	3,570	265	7.4
Norway	1,200	33	2.7
Portugal	2,130	53	2.5
San Marino	6	0.1	1.3
Spain	7,502	180	2.4
Serbia & Montenegro	1,672	160	9.6
Sweden	1,941	43	2.2
Turkey	26,784	460	1.7
United Kingdom (Scotland)	1,132	-	-
United Kingdom (nation wide)	13,300	930	7.0

* Meaning of figures:
Andorra: children in special programmes in regular schools or in specialised institutions
Austria: receiving increased family allowance
Belgium (Flemish region): bases on population survey
Belgium (Walloon region): 0 - 19 years
Belgium (German speaking region): registered at Office for People with Disabilities OPH
Bulgaria: total: 0 - 14 years; with disability, registered as disabled

Croatia: Users of social services
Cyprus: 0 - 14 years
Finland: receiving child disability allowance
France: children for whom special schooling arrangements are required
Germany: registered as 'severely disabled'
Luxembourg: beneficiaries of supplementary allowance for disabled children
Moldova: total: 0 - 14 years; with disability: 0 - 16 years, registered as 'degree I, II or III invalidity'
Netherlands: 40,000 with intellectual disability and 225,000 with physical disability 6 - 19 years, based on population survey
Portugal: figures from national census 2001
Spain: figures from Disability, Handicap and Health Survey 1999; children from 6 - 18 years
Sweden: receiving childcare allowance
UK (Scotland): 45,348 children with limiting long-term illness 0 - 15 years; 890,242 disabled people (adults and children)

The table shows considerable variation in the relative frequencies of children with disabilities in the various countries, ranging from less than 1% (in Albania, Andorra and Georgia to about 7% (in the Netherlands, Serbia & Montenegro, the Walloon Community in Belgium and the UK). However, it is difficult to compare the figures, considering their differences in meaning. As the specifications show, in some cases the numbers apply to persons who receive specific benefits, and in other cases they are derived from the outcomes of a population survey. Thus the data cannot be regarded as a reflection of real differences in prevalence of disabilities among the children in the various countries.

3. Systems of service provision

The questionnaire ended with questions about available services in this field and the way in which they are financed.

Q7 deals with services for children with disabilities. Respondents were asked to supply information about the major services in their country by indicating for each of the major service-providing organisations:

a) its types of service and target group;
b) proportion delivered by mainstream provision and specialist provision;
c) proportion delivered through residential placements;
d) provided by central government, local government, private organisations, voluntary organisations or charities;
e) number of clients (children with disabilities).

Available services for the parents of children came up in Q8. It was asked whether the support to families includes:
a) information about service provision options;
b) help with finding and accessing services;
c) benefits / grants to meet additional costs of having a child with a disability
d) other type(s) of support (to be specified)

With Q5 the roles of the governments at different levels (central, regional and local) was ascertained. And Q9 asks how the services are funded.

3.1 Types of services

The reactions to Q7 clearly revealed that those questions were difficult to answer. In most cases the reply was quite incomplete. Not even one respondent has supplied full answers. Several persons explicitly stated that the questions are too detailed to answer or that the required data are not available. But most respondents showed their difficulty with the questions without saying, by leaving them unanswered. This applies especially to the questions b, c and d. Thus the results do not supply a sound basis for a detailed picture of the available services in the various countries. We can just give a broad outline of the service provision.

Replying to Q7a, most respondents mentioned the major services for disabled children or for disabled people in their country. Some just named the services, others supplied some details about scope, target groups etc. Based on this information we can give an overview of types of services that generally exist in the participating countries.

Of course the field of *education* is especially significant for the age-category in this study. Both nursery schools, primary schools and secondary school are relevant. Almost all respondents mentioned one or more facilities for pupils with disabilities. They include assistance, facilities and technical aids at regular schools, special classes, special schools and boarding schools for children with particular disabilities.

Facilities in *health care* are also prevalent. Services include therapies, rehabilitation, prevention, early detection, and -counselling.

Social services is an umbrella term for a variety of services, including assistance with personal care, domiciliary care, advice and counselling, visiting day care centres. Systems for support vary: Support can be provided by delivering the required services or by granting payments to purchase the services or for additional expenses.
Practical support include facilities in transport, housing with special arrangements, recreational facilities (like sports)

Vocational training was also mentioned by some. Within the age-category of this study, work-related services are relevant for the adolescents.

According to the answers to Q8, the available *services for parents* of disabled children at least include the supply of information about serve provision and help with finding and accessing services (types a and b). Moreover, in several countries parents can receive *allowances* (direct payments) to compensate for additional expenses or purchase the necessary care for the child. In some countries parents are supported by providing *respite facilities or breaks* to them.

3.2 Three distinct 'models' in service delivery

If we look at the *dimension mainstream provided and community based services versus special and residential services*, the countries that participated in this study can be grouped into three broad categories.

Hybrid systems in Western European countries

One category covers most Western European countries. In these countries we find all kinds of services, both mainstream and special, both community-based and residential. Although a development towards more community-based provision is pursued, it seems that the institutions remain fulfilling a role in the service provision for particular disabled children. This position is expressed in the contribution of Belgium (Flemish region). Flanders has an educational system that supplies assistance for disabled children in ordinary schools (mainstream provision) and in special schools (specialist provision). Similarly, the system for health-related long-term care and social care comprises services that are offered in the community (like personal care and psycho-social support), semi-residential services (provided during the day-time, e.g. semi-boarding schools) and residential services (like boarding schools). The Walloon region of Belgium has a similar variety in service provision. It includes:

- Early assistance services, reserved for children up to the age of 8
  The general mission of the early assistance services is:
    - to provide educative assistance through mainly individual interventions that essentially take place in the home environment of children with mental, physical or sensory disabilities from the time the disability is first diagnosed until the child is eight;
    - to provide the families and environments of children with disabilities with educative, social and psychological assistance in order to make them better able to resolve disability-related problems and thus foster the optimal development of the child in his/her home environment;
    - to promote the prevention and screening of disabilities of every kind before, during and after pregnancy and to be involved in or collaborate with every initiative with this objective;

    Early assistance services may also develop collective actions or community work, particularly with the objective of training and informing parents and the child's various environments: crèche, school, etc.
- Integration assistance services, reserved for young people (aged from 6 to 20) to promote their participation and socialisation in mainstream everyday environments. The services offer:
    - individual assistance outside school time;
    - individual assistance through individual or group activities during school time;
    - formulating collective responses to individual needs outside school time;
    - development of community work.

- Youth day centres, reserved for young people who attend a mainstream or special school. To pupils who are temporarily excluded from the school the services provide individual educational, medical, therapeutic, psychological and social.

- Day centres, reserved for young people who because of their disability do not attend a mainstream or special school. The services provide individual educational, medical, therapeutic, psychological and social care.

- Residential services, reserved for young people. It provides housing (including short stays) , educational, medical, therapeutic, psychological and social care that supplements their schooling.

In the questionnaires of several surrounding countries (like Germany, Austria, the UK and the Netherlands) both mainstream and specialist provisions, including residential an semi-residential accommodations, are mentioned as well.

Sometimes the institutions not only deliver services to its residents, but also to children in mainstream settings. An example is Portugal. The special education institutions in Portugal are gradually changing into resource centres, where specialised professionals, equipment and teacher training are available to help mainstream schools and provide community-based services through partnership agreements.

Most of these countries have another thing in common. On the dimension public - private service provision the systems can be labelled as hybrid. Private, most non-profit organisations are delivering the social services, but the government (central, regional and/or local) government is responsible for the policy, and the service provision is mainly paid out of public funds (taxes or social insurances). In Germany and in the Netherlands the so-called principle of subsidiarity is held. It signifies the belief that private organisations should adopt tasks first, and only if this is not possible, governmental organisations should come into play.

Spain and Portugal differ somewhat in this respect. In these countries social services and family support are partly delivered by municipalities or state local social services. However the main part is provided by private non-profit organisations. In Portugal this also applies to special education: the mainstream schools are public, but the special schools are private non-profit organisations.

Moreover, the UK does not quite fit in the hybrid model. In the UK, the state not only plays a key role in funding health and social services, but also in providing it. In this respect the system more resembles the arrangements in the Northern European countries (below). The state has delegated the responsibility for the health care to the National Health Service (NHS). NHS-bodies deliver health-related services to disabled children. Social services form part of local government. Local Authority social services departments are responsible for the provision personal care and other social services. However, increasingly social services are purchased from private agencies. Thus the actual delivery is coming closer to that in other Western European countries.

Public provision in Northern European countries

The Nordic countries comprise a second category: Norway, Sweden and Finland. These countries have proceeded most in de-institutionalisation and mainstream provision of services. Long-term residential placements of children with disabilities are almost abandoned. Sweden closed the institutions several years ago: "The Act of Abolition of the Institutions (1997) put as final deadline for closing institutions the 31st of December 1999 (for adults). Concerning children the deadline was earlier". And according to the supplied data, in Finland less than 100 children (0,02% of all disabled children) are placed in long-term institutional care.

Systems of community-based services are expanded to supply the necessary assistance. All countries have a comprehensive service-package. This is illustrated in the Finnish questionnaire:

- Education of children with disabilities is mainly arranged together with non-disabled children in mainstream settings, ensuring that the child receives the necessary special services and support they need (e.g. personal assistants, assistive devices, transport services, rehabilitation) and that the personnel has sufficient training. For those children whose educational needs cannot be met within the mainstream educational system, alternative forms of education are offered in a special class within an ordinary school or in a special school, for instance where sign language is used.
- The municipality provides free interpreter service for deaf-blind and for young persons with serious hearing impairments or severe speech impairments if it is necessary for coping with studies after the basic compulsory education. The municipality may at its discretion reimburse a disabled young person for the costs of employing a personal assistant and arrange transport services. These support services make vocational and university studies possible also for students with disabilities.
- In 2004 a new Act on the Afternoon activities for first and second grade pupils entered into force. It is the responsibility of the municipality to offer after noon activities to all

children for the two first school years. Pupils with special needs are entitled to after noon activities for the six first school years.
- Some municipalities offer sports instruction for children. Disabled children can participate in sports activities together with non-disabled children or in special groups. Participation is supported by personal assistants and transport services.
- A seriously disabled child's family must be reimbursed for the cost of alterations to the dwelling caused by disability. He or she has the right to obtain equipment and devices that are necessary for the person's independent living.
- Adaptation training is usually arranged in the form of residential courses. Training helps disabled children and their families to lead a full life despite the disability. Through rehabilitation counselling children with disabilities are guided towards the appropriate services. Rehabilitation counselling is arranged mainly through health care and disability organisations. An individual service and rehabilitation plan is being drawn up together with the disabled client and the relevant authorities".

In Sweden a similar broad service system exists: "The Swedish Education Act stipulates that consideration must be afforded to pupils with special needs and that all students in need of special support must have written plans of development set up in co-operation with the pupils themselves, parents and professionals. The current curriculum for compulsory schools does not use the word mainstreaming, but takes for granted that all students will be educated in regular classes. If this is not possible, the school has to motivate very clearly why another solution is chosen for certain students. Most pupils in need of special support are taught in the regular compulsory school and upper secondary school, but special teaching groups are also organised to some extent for pupils with functional impairments.

Deaf and hard-of-hearing children with sign language as their first language are taught at one of the five regional state-run special schools. There is also one national special school for deaf and hearing-impaired pupils who are also severely learning disabled.

The special kinds of services covered by the law are:

- advice and other support that requires special knowledge about problems and conditions governing the life of a person with major and permanent functional impairments;
- help from a personal assistant or financial support for reasonable costs for such help;
- assistance on special occasions such as walks, visits to cultural institutions, recreation facilities, etc.;
- help from personal contact (companion/friend);
- relief service in the home;
- short stay away from home;
- (short period of) supervision for schoolchildren over the age of 12 outside their own home in conjunction with the school day and during the holidays;
- foster homes and housing with special arrangements for children and young people who need to live away from their parental home.

From an organisational perspective, the descriptions show that the Nordic countries do not have a hybrid system of service provision, as in most Western European countries with their pivotal role for private organisations. In the Nordic countries the services are mainly delivered by the municipalities. Private organisations only play a minor role.

Also in funding the services, the three Nordic countries are alike. Their major sources of finance are municipal taxation and government grants.

Transformation process in central and Eastern European countries

The third category comprises the countries in central and Eastern Europe. A common element in their answers to the questionnaire the emphasis on legislation in the field. Some explicitly mention the relevant laws, others portray the services that should be delivered according to the laws. An example of the latter is the Czech Republic:

Current legislation:

- The special educational needs of children, pupils and students shall be ensured by a school advisory facility.
- Children, pupils or students with special educational needs shall be entitled to an education the content, form and methods of which correspond to their educational needs and possibilities, provided that necessary conditions enabling such education are created and the advisory assistance of the school and the school advisory facility is available.
- Disabled children, pupils or students shall be, during their education, entitled to the free use of special textbooks and special didactical and compensatory teaching aids provided by the school. Children, pupils and students who are deaf-and-mute shall be entitled to free education through or by means of sign language. Visually impaired children, pupils and students who cannot read normal print shall be entitled to education using Braille print. Children, pupils or students who cannot communicate in spoken language shall be entitled to free education through or by means of compensatory ways of communication.
- Should it be required by the nature of schools for the disabled or, with the consent of a Regional Authority, classes, departments or study groups at schools using adapted educational programmes shall be established for disabled children, pupils or students. Pupils suffering from serious mental disability, pupils with several learning disabilities, and autistic pupils shall be entitled to be educated at a special basic school if they are not thus educated otherwise.
- Head teachers of nursery schools, basic schools, basic special schools, secondary schools, and tertiary professional schools may, with the consent of the relevant Regional Authority, establish the post of teacher’s assistant for classes or study groups where a child, pupil or student with special educational needs is educated.

In the contribution of Croatia objectives in the relevant programmes are described: the National Strategy of Coherent Policy for the Disabled, the National Programme of Action for Children, and the National Education Standard.

The emphasis on legislation probably reflects the achievements in adopting new laws in the process of transformation. Consequences for the change in types of services for disabled people are also shown in the Czech contribution: "Residential care has had a long tradition in the Czech Republic, but at present a strategy of transformation of residential care is prepared towards providing community services and services at homes of clients (non-legislative governmental task to be fulfilled by the end of 2005). The system of social services will be changed only by a new legislation (the Act on Social Services), which will be in force from 2007".

More community-based services for disabled children are established now. Like in Bulgaria, where the number of day care centres for children and youth with disabilities is augmenting.

These centres offer:

- medical services, like rehabilitation and therapy;
- educational services: individual educational plans, education in helping schools, integrative education in ordinary schools;
- organisation of various events aiming at presentation of specific needs of people with disabilities;
- work with parents and relatives of children with disabilities (individual, group and family consultations).

In Croatia, like other central and Eastern European countries, the number of institutional placements is continually decreasing whereas the number of users who benefit from services of day care, support and in-house help, family care, foster placement, independent living and other non-institutional forms of care is increasing. And specialists from institutions are involved in community-based services.

Furthermore, descriptions of these countries reveal a process of decentralisation: Regional and local governments are assigned important roles in the service provision. At the moment the central governments of Albania, Estonia, Latvia and Moldova are still responsible for the institutional care and /or other care for people with a mental disability.

In sum, significant transitions take place in the systems of service delivery in central and Eastern European countries.

Turkey does not exactly fit in one of the three groups. In the first place, it should be noted that Turkey has by far the largest population among the participating countries, a relatively young population, and according the largest number of disabled children, estimated at 460,000 (see the table in section 2). However, the capacity of service provision for them is still quite low, considering that the number of users of special care or education is about 25,000. This explains why the government encourages the establishment of new centres for care, rehabilitation and family counselling.

The principal organisation in this area in Turkey is Social Services and Protection of Children Institution (SHÇEK). It is a state organisation which establishes, licenses and runs care and rehabilitation centres for persons with physical disabilities, mental retardation or psychogenic disorders. There are several types of centres:

- care and rehabilitation centres;
- training and rehabilitation centres for spastic children, providing medical care and rehabilitation to children of 0-14 years, guidance to their parents and guidance and training to spastic adults;
- rehabilitation centres for blind, providing training to improve self-sufficiency and assistance in solving their psychological and social problems;
- private rehabilitation centres licensed by the Institution SHÇEK, providing services for mentally retarded children and spastic children;
- nurseries and day care centres;
- family counselling centres, helping the families in solving their problems.

Local authorities are responsible for implementing the law and they can provide benefits to families with disabled children, like reduction in transportation fares and financial contribution for expenses. Private rehabilitation and care centres supply the services. Thus in this respect the Turkish system matches the hybrid model from the Western European countries.3.3 Role of central and local governments

More information about the role of the governments at different levels (central, regional and local) was produced in response to Q5.

In general, the division of responsibilities conforms the Austrian sketch: "The system of social protection is characterised by a blend of centralised and decentralised elements".

The role of the central government is mostly described as a steering and facilitating one. The central government is responsible for the relevant legislation process and the development of policy in disability issues. Moreover, the central governments are responsible for the arrangements in education: special services in mainstream schools and specialised schools. Systems for monitoring the quality of the services also belong to the domain of the central governments in many countries. In some central and Eastern European countries the central government is still responsible for the provision of certain care. As we already stated, this applies especially to residential care.

Usually, the regional and local authorities are responsible for the more detailed planning of services in their territories. For England is this responsibility described as follows: "Local authorities will have the central role in commissioning and co-ordinating the delivery of integrated early years and childcare services and address the lack of affordable and accessible child care for disabled children".

As we already said, in the Nordic countries most social services are delivered by the municipalities themselves, whereas in Western European countries the services are usually delivered by private non-profit providers. The UK stands midway between: both local authorities and the private sector provide social services.

Furthermore, the answers show a certain distinction between health care and social care. Apparently health care services are often regulated at central level, whereas social services are more managed at the local level. This applies for instance for Belgium, Austria, Serbia & Montenegro and the UK. The trend is even visible in Nordic countries, where the position of the local authorities is relatively strong. Like in Norway: "Secondary and specialist health services and specialist medical rehabilitation are organised into five state-run regional health enterprises. The local authorities provide other services such as pre-schools, schools, health- or social services, practical help and relief assistance".

And in Sweden concerning the local and regional level: "The local authorities have primary responsibilities for education, housing, children, child care and social services; the county councils for health care, and rehabilitation and assistive technology". In Finland the Social Insurance Institution [a central body] is in charge of medical rehabilitation.

3.4 Funding

How are the services for children with disabilities are funded in the participating countries?

In most of them the central government provides the major resources. Finances from general taxation and/or social insurances are reserved for these services. Local governments also contribute, e.g. in the UK. In the Nordic countries the municipalities are even the major financial source. They can provide the means through local taxation. Sweden has a detailed system of funding. It is described as follows: "Municipalities and county councils have a considerable degree of autonomy and have independent powers of taxation. Local self-government and the right to levy taxes are stipulated in the Instrument of Government, one of the four pillars of the Swedish Constitution. Concerning state grants for the service provision: Grants from the state are either general or targeted. The general grants are paid per inhabitant. Each local authority or county council/region can use this money on the basis of local conditions. Targeted grants must be used to finance specific activities, sometimes for a specific period of time. And about the funding principle in Sweden: The funding principle means that if the state decides to impose new tasks on the local authorities and county councils/regions, then the state must also provide the funds required to carry out these tasks. Moreover, a system of tax equalisation was introduced. There are major variations in the average income of the inhabitants of the various local authorities and county councils/regions. The cost per inhabitant for the services they are entitled to also varies. In order to ensure fairness, a system has therefore been introduced with the aim of providing equitable conditions in the different local authorities and county councils/regions. This is the local-government equalisation system, which entails redistributing the revenues of the local authorities and county councils/regions on the basis of their tax base and level of expenditure. The equalisation system is managed by the state".

In most countries, client fees form additional financial sources, especially for social services users often pay a financial contribution. In some other countries resources are received out of donations from national and/or international organisations as well as persons.

4. Key policies and good practices

We have tried to explore the aims and scope of key policies concerning children with disabilities by the questions:

Q4a Please summarise the key policies being implemented in your country to support the development of services for children with disabilities.

Q4b If the policies detailed in answer to Q4a include measures aimed at changing provision from a system of mainly residential provision to community based provisions, please give brief details on the specific areas you would like to identify as examples of good practice?

In the answers to Q4a four issues can be identified:

- human rights approach by pointing to the significance of equal opportunities for people with disabilities, independent living, and fighting discrimination;
- de-institutionalisation, provision of services in the community;
- provision of mainstream services versus special services;
- types of services (description).

4.1 Statements about equal opportunities

On the whole, the formulated key policies in the various countries reveal a certain similarity. *Social participation* is a central concept in describing the aims of the policy: People with a disability should be enabled to lead a life within the community as independent as possible.

The main difference between the answers is their focus on the leading principles of the policy in their country or on available services.

Examples of the first category are from Finland, Turkey and Germany.

Finland: "The goal of Finnish disability policy is to promote the independence, equality, empowerment and participation of persons with disabilities by supporting them in taking initiatives, by giving them more power to make own decisions and by removing physical, attitudinal and communication-related obstacles to their participation. Key words: Empowerment and equal participation".

Turkey: "Aims and key policies are to provide full participation in social life, accessible physical environment, full participation in education system and equal opportunities.

In the German answer the term 'paradigm shift' is used, a change explained by the phrase: "Welfare and care for disabled persons no longer constitute the focus of political efforts, but rather their self-determined participation in the life of society and the removal of all obstacles which conflict with their equality of opportunities". Along the same line, the reply from Spain designates the promotion van non-discrimination and equality of opportunities for people with disabilities.

4.2 Emphasis on tailor-made services

The Flemish region in Belgium is an example of the second category: "We try to provide services that are *tailored to the expressed and assessed needs* of disabled children and their families. A whole range of services has been developed, on a continuum starting with assistance at home and ending with institutional care 24h a day".

That the services should be tuned to the individual's needs is also expressed in some other descriptions. The German answer comes up with a 'plan for individual help' and the Finnish answer with 'individually tailored service plans'. Similarly, according to the Scottish key policy in education "It will always be necessary to *tailor provision to the needs of the individual child*" and the main goals in Croatian policy is "better quality in meeting the children’s needs in all life domains (health care, education, living conditions, protection from violence and neglect); to ensure adequate conditions for proper development and growth in exceedingly difficult circumstances …" And the National Service for Children, Young People and Maternity Services in England states that: "children and young people who are disabled or who have complex health needs should receive co-ordinated, high quality child and family centred services which are *based on assessed needs* …". In the same context, the Norwegian answer refers to outcomes of an evaluation study: "The families are not on the whole dissatisfied with the services they receive, but they experience that they have to face a time-consuming process and many barriers to get *the help they need*. They believe it's important to receive a more co-ordinated range of services across sectors, receive more flexible services and better information".

According to the Act on Social Services in the Czech Republic the assistance should be available, effective, of good quality and economical.

4.3 Positions in mainstream and special services

Preference for mainstream settings is most strongly emphasised in the Norwegian answer: "Children with reduced functional ability live with their families in their local community. Local authorities provide services to support the families. The services mainly include health care, practical support, relief assistance, support persons, schools and nursery schools. The aim of the policy is to support the families so they are able to take care of their children at home. The child shall be able to participate fully in the local community; participate in the ordinary nursery schools and receive services from the mainstream provision".

Several others also state a preference for mainstreaming. But at the same time they propose *special services* for certain cases. In the policy of the Netherlands this approach is expressed as: "Mainstream wherever possible, special where necessary". A similar slogan is worded in German speaking region of Belgium: "Using existing services whenever possible and special services when necessary".

The key policies concerning education in Scotland also conform to this principle. It's standards include:

- The intention behind the mainstreaming duty is to establish the right of all children and young persons to be educated alongside their peers in mainstream schools unless there are good reasons for not doing so.
- However, it also specifically allows for education to be provided elsewhere, if either, mainstream schooling is unable to meet a child’s needs, or where their inclusion would be incompatible with the education of other children.
- It will always be necessary to tailor provision to the needs of the individual child, and to make available a range of mainstream and specialist provision, including special schools, to meet the needs of all children.

To improve access for pupils with disabilities to of school life, local authorities had to produce accessibility strategies by April 2003. The strategy must consider how to improve access time in three ways: improving access to the curriculum, physical access, and improving access to information and communication for pupils with disabilities".

In Luxembourg, a similar policy is pursued, including the criteria for referral to special schools: "The Act on Educational Integration promotes the participation of children with a disability and special educational needs in mainstream education as well as their integration in pre-, primary and post-primary schools. " A special school is advised in cases that "a children whose disability is so serious that he or she is unable to follow lessons or whose presence would seriously disrupt the life of the school". The education system in Luxembourg offers not only the possibility of complete integration in mainstream education and admittance to a special school, but also an intermediate solution: "partial integration of a child with a disability in a regional centre or special education institution and also, for some activities, in a mainstream class". In France a similar partial integration exists, enabling children in medico-social or medical establishments to participate in certain activities at ordinary schools.

Also the policy in Portugal is directed towards inclusive education. "Education of children with disabilities is mainly arranged together with non-disabled children in mainstreaming day care centres, pre-school and school settings near their homes, ensuring that they receive free of charges the necessary special services and supports they need (e.g. specialised teachers support, psychologists, therapists, sign language teachers, sign language interpreters, teacher assistants, special materials, assistive devices). …For some children with severe and profound deafness, multiple disabilities, autism or deaf-blind, there are alternative forms of education offered in specialised units within ordinary schools…The specialised units make possible the attendance of these children in schools not very far from their homes avoiding their transference to segregated special schools…Only in exceptional circumstances when mainstream education has confirmed not to be able to supply pupils with the educational responses they need, are they allowed attending private and non-profit special schools free of charge for families during the compulsory schooling age."

Finland's position is similarly described : "Education and day-care for children with disabilities are mainly arranged together with non-disabled children in mainstream settings, ensuring that the child receives the necessary special services and support he or she needs (e.g. personal assistants, assistive devices, transport services, rehabilitation). For those children whose educational needs cannot be met within the mainstream educational system, alternative forms of education are offered in a special class within an ordinary school or in a special school, for instance where sign language is used".

In Sweden are also exceptions to the rule of mainstreamed policy. Special support and services are available for people with disabilities. And about the situation concerning education: "The Swedish Education Act stipulates equal access to equivalent education for all children and young persons, regardless of sex, geographical location and social and economic circumstances. The municipalities are responsible for the education of pupils with disabilities. The Education Act also stipulates that consideration must be afforded to pupils with special needs and that all students in need of special support must have written plans of development set up in co-operation with the pupils themselves, parents and professionals. The current curriculum for compulsory schools does not use the word mainstreaming, but takes for granted that all students will be educated in regular classes. If this is not possible, the school has to motivate very clearly why another solution is chosen for certain students. Most pupils in need of special support are taught in the regular compulsory school and upper secondary school, but special teaching groups are also organised to some extent for pupils with functional impairments. Deaf and hard-of-hearing children with sign language as their first language are taught at one of the five regional state-run special schools. There is also one national special school for deaf and hearing-impaired pupils who are also severely learning disabled. The emphasis on teaching in sign language, and thus need for contact with other deaf children with the same method of communication, has meant that the special school has been retained".

Estonia has special education for several categories children with disabilities: " … municipality and city governments shall allow children with special needs to attend the school of their residence. If suitable conditions are not found, disabled children and children who need special support have the right to attend the nearest school which meets the requirements. … Children with special needs shall be recommended a curriculum or school suitable for their abilities … Schools for students with special needs are intended for students with physical disabilities, speech impairments, sensory or learning disabilities, or mental disorders, and for students who need special treatment due to behavioural problems. Sanatorium schools are intended for students with health disorders where students study and receive the necessary treatment".

Living in an institution can be regarded as the most clear-cut deviation of mainstreaming. In general, residential placement is not preferred, because it segregates the child from its natural environment. In the answer of several countries this position is articulated, as shown in the following examples.
Czech Republic: "Aim is to provide services which enable persons with disabilities to live in their natural environment and, if this option is not feasible, to provide services offering them an opportunity to participate in social life …"

Germany: "There are rules intended for services in the family, partly residential or residential support in each personal case. These rules lead to the policy that more and more ambulatory support increases. Therefore the cases in residential services are decreasing".
Italy: "General Law 104/92 predisposes services that assure social integration of children with disability (foster care and inclusion in family contexts, community living, housing)".

Latvia: "Social services shall be provided in the place of residence of the client or as near to it as possible. Only when the scope of such services is not sufficient the social care and social rehabilitation shall be provided in a long term care and social rehabilitation institution. Orphans and children with disability left without parental care shall be provided with respective care in a family like environment – in a foster family, with a custodian, and only when the above is not feasible, the care shall be provided in a long term social care and social rehabilitation institution".

Moldova: "The Project Law on Protection of the Child in difficulty would bring the following: decrease in number of institutionalised children, restructuring of residential institutions in order to provide a family type environment …"

Netherlands: " … stimulation of community care or living at home; increase of day care for children".

Spain: "Home help has been encouraged for several decades. It is provided by the municipalities to people in need of special care, helping to avoid placement in institutions."

Sweden: "All residential provisions have been transformed into community based provision. The Act of Abolition of the Institutions (1997): put as final deadline for closing institutions the 31st of December 1999 (for adults). Concerning children the deadline was earlier".

The UK: " … children and young people who are disabled or who have complex health needs should receive … services … which promote social inclusion and, where possible, which enable them and their families to live ordinary lives".

4.4 Deinstitutionalisation and innovations in community-based services

We now turn to the question about good practices in de-institutionalisation. Replying to Q4b, most respondents reported about innovative kinds of community-based services in their country. Our distinction into three 'models' (see section 3) is also applicable here.

As already mentioned, the *Scandinavian countries* took direct measures in reaching de-institutionalisation by closing the residential institutions. This was already done before 2000. As a result, disabled children in Norway, Sweden and Finland live in their families or other community settings. A comprehensive package of community-based services was established to provide in the required care (see section 3 for more details).
However there are still problems with the access to the services and the co-ordination. Finland tries to improve the situation by case management and service co-ordination. "The Ministry of Social Affairs and Health carried out a project with case management and service co-ordination for children and young people with long-term illnesses or disabilities and their families in co- operation with thirteen partners (2001-2003)… Families were advised to examine their situation and together with the service advisor they outlined their needs and recourses, as well as future objectives. The service package for each family was reflected in individually tailored service plans. The project is till running and has now extended to new groups (e.g. older people) and more municipalities".
Moreover, in Finland the support of carers is improved. "Finnish legislation on the support for informal care stipulates municipalities to provide compensation for the carer and services for the person cared for e.g. home help, service housing and respite care services. Carers are entitled to two days leave per month during which the municipalities has to provide for alternative ways of taking care of the child/person".

The innovations in the *Western European countries* mainly focus on gaps in the service provision. By introducing new or improved services it is tried to offer satisfactory alternatives for placements in residential institutions and special schools, and thus encourage community-based, inclusive arrangements.
Several countries reported that this approach works. For instance the Flemish Community in Belgium: "By introducing more variety in the services and by making them more tailored-made, we could reduce the number of residential places". And also in Germany a substantial increase in ambulatory support services has occurred in the last years.
In France the effects of the introduction of support services in ordinary schools are quantified: "As a result the number of children with disabilities enrolled in ordinary schools increased by 44% in primary education and 70% in secondary education between 2003 and 2005: (almost 134,000 pupils, compared with 89,000 in 2002-2003)". Mainstream education in France is encouraged by introducing technical and human aids in ordinary schools, group integration schemes, medico-social school support services and renewed training for specialised teachers. Moreover, families with a child that requires special education arrangements (outside boarding schools) can receive an education allowance.

Other replies address to community-based health and social care. Like Austria: "The Federal States support families with assistants to reduce residential living…. Many types of services are offered, such as paediatricians, therapists and social workers who come to the homes of the children to offer their help".
Spain also gives priority to avoiding placement in institutions by providing in the needs of disabled people and their families for care and support. Home help and social and health services are available. A new system of benefits is now on the drawing board.
In Ireland the service delivery will also be revised: "The provision of health and personal social services to children with a disability is currently being reviewed under the Governments Sustaining Progress Programme. The outcome of this review will lead to the

formulation of a Strategy for the development of future services for people with a disability, including children".

Luxembourg offers a comprehensive package of community-based services, including:

- early intervention, whose purpose is to react as early as possible in order to avoid deterioration and the secondary effects of an impairment;
- early assistance (0 – 4 years) includes all forms of assistance and support for young children and their families;
- several facilities for disabled children in mainstream education;
- specialised transport to school and work;
- housing (there is a trend towards decentralisation of large specialised institutions);
- financial allowances and benefits (supplementary allowance when a child is disabled, child-rearing allowance, and benefits from the long-term care insurance like assistance with ADL and with domestic tasks)

Moreover, Luxembourg tries to improve the access to services and the service co-ordination by several means:

- Since 2003 there has been a National Information and Contact Centre on Disability (Info-Handicap) whose prime task is to systematise the gathering and consultation of data and establish a communications network in order to fill a gap and respond to the need for full, centralised, updated information that can be accessed easily and quickly.
- The 'Cord' pilot project, which is directed at ongoing support for the family from a 'co-ordinator'. The project focuses on children with special needs and their families and has two essential aims:
  1) to analyse the factors likely to help the families of children with special needs, and
  2) to explore a model for co-ordination of all the services and assistance required by children with special needs and their families.
- The Disability Guide: This regularly updated handbook could be called a reference book that tries to guide people with disabilities and their families through the maze of services available to them and to explain their rights.

Access is also an item in the Scottish policy for the mainstreaming of education. "Aims are to improve access for pupils with disabilities to all aspects of school life. Local authorities had to produce accessibility strategies by April 2003, and then implement them. Strategies generally cover a three-year cycle. The strategy must consider how to improve access over time in three ways: improving access to the curriculum, physical access, and improving access to information and communication for pupils with disabilities".

The reply from Portugal denotes the following good practices that have a direct or indirect contribution to enhance the community-based provision:

- Community Social Network, aiming at improved co-ordination: a legislative measure establishing a network organisation of local public services, private non-profit organisations and other entities with the co-ordination of each local authority.
- Early childhood Intervention (ECI) system, aiming the prevention of secondary conditions and the promotion of the development of children in early years, under a family-centred approach and comprehensive model. ECI provides an effective way to empower families and improve community services delivery that could reduce future institutionalisation.
- Increment of inclusive education policies and practice has been an important contribution to decrease the number of institutionalised children with disabilities, as well as the number of boarding schools. Even children with severe disabilities can be attained in specialised units within ordinary schools near their homes.
- Conversion of some special institutions as 'resources centres', providing community-based and more comprehensive services.
- Special benefits and arrangements for working parents with severe disabled children, aiming the conciliation of professional life and family life: permission for one of the

parents stays at home till 6 months with a grant paid by social security and flexible arrangements of work timetables.

Special attention is called for the special institutions working as 'resource centres' in community-based settings. A similar mode of operation is applied in some other countries. Like in the education in France: "Schooling in ordinary schools, for example, is often combined with supervision by a specialised service, or a health service, which is often instrumental in successful integration, making it possible to cater for the child's specific needs in terms of education, re-education and therapy. Concurrent attendance at a school and a specialised establishment is also a possibility".

Italy reported the following areas of good practice:

- personalised plans for house attendance and personal aid, for supporting families with disabled sons;
- socio-educational integrated centres for infancy and adolescence;
- interventions in order to favour the sport for children with disability in children' recreation centres.

And from the Netherlands were mentioned:

- the so-called "rucksack", a special toolkit (extra funding) for disabled children in regular schools to be spent for extra support and educational services;
- respite provision: short-term (lodge) accommodation for disabled children to relieve the parents for a weekend;
- early intervention programme;
- 'Family's First' (form of family support)".

Several of the former contributions point to early assistance. In the UK a specific 'Early Support Programme' is developed:

- The programme provides funding and support to encourage local education, health and social services to improve services for very young disabled children and their families through partnership, based on implementation of the good practice.
- The published intention is that the programme should be mainstreamed as part of the 10-Year Childcare Strategy. In consultation with parents and local providers, all local authorities are now encouraged to use the Early Support materials and approaches and to jointly review and improve the services they provide for disabled children and their families.

Early assistance services were also specified in the reply from the Walloon Community in Belgium.

The replies from the *central and Eastern European countries* revealed that a process of de-institutionalisation is going on.

From the Czech Republic: "Residential care has had a long tradition in the Czech Republic, but at present a strategy of transformation of residential care is prepared towards providing community services and services at homes of clients …".

From Georgia: "The major goal [of policy on disabled children] is social adaptation which includes …. deinstitutionalisation, development of community-based organisations for those who have reached adulthood".

From Moldova: "The development of community social services lays on the basis of the national policy and makes its priority goal. Providing community services to children with disabilities will contribute to immediate decrease of number of children placed in social institutions to and integration and maintenance of children with disabilities in the community".

And from Latvia: "Social services shall be provided in the place of residence of the client or as near to it as possible... Orphans and children with disability left without parental care shall be provided with respective care in a family like environment – in a foster family, with a custodian. Only when the above is not feasible, the care shall be provided in a long-term social care and social rehabilitation institution".

In their replies, Albania and Serbia & Montenegro mentioned particular community-based provisions in their countries, like allowances, domiciliary care, housing and vocational rehabilitation.

Estonia points to a shift in funding: "Until 1998 only nursing home (institution) service were financed from the state budget among the state welfare services provided to persons with special mental needs. The services of day centre were added to the list of financed services in 1999 and the rehabilitation service in 2000".

Effects of their policy are mentioned by Croatia: "The number of users with institutional placement is continually decreasing whereas the number of users who benefit form services of day care, support and in-house help, family care, foster placement, independent living and other non-institutional forms of care is increasing." Nevertheless, de-institutionalisation of social care is still a novel process in providing care for people with disabilities and mental disorders. A study is conducted in order to define the scope and dynamics of de-institutionalisation and professional and financial feasibility of community care.

The same trend of decreasing numbers of children places in specialised institutions occurs in Bulgaria. In the last 3 years there was a decrease from 11,834 to 9,525. In Bulgaria the development of community-based services is already prepared some years ago. There are several social services for disabled children, like day care centres, centres of social integration and rehabilitation, and an allowance for social integration.

As already stated, *Turkey* does not exactly fit into one of the three 'models'. Similar to the central and Eastern European countries, the policy in Turkey aims at expansion of the community-based services. The government encourages the establishment of new centres that provide social care, rehabilitation and family counselling.

4.5 Consultation of target groups

Almost all respondents stated that disabled children and/or their families are consulted when developing policies that concern them (Q6a). And consultation with their interest organisations is just as common, according to the answers to Q6b.

Most countries have councils or committees for disability issues, in which associations of disabled people and parents of disabled children are represented. Those bodies advise in matters concerning disability policy. In other countries consultations take place on ad hoc basis.

The Nordic countries have elaborate systems of consultation Like in Finland: "Consultation takes places at three levels: on the individual level, at the local level and at national level. At national level there is the National Council on Disability linked to the Ministry of Social Affairs and Health, consisting of eighteen members. It is a co-operative body between the relevant authorities and disability organisations. At local (municipal) level there are about 220 municipal councils on disability, in which the different sectors of local administration and NGO's co-operate. On the individual level there are adaptation training courses for children with disabilities and their families which are funded and arranged by municipalities, the Social Insurance Institution and disability organisations. Municipal authorities draw up individual service plans for disabled persons together with the person and/or his/her family members".

5. Conclusions and questions for the drafting of recommendations

5.1 Positive attitude toward community living and mainstreaming

Looking at the findings from the questionnaires, a general conclusion might be that the countries show a certain agreement in their attitudes towards community living for children with disabilities. They gave testimony to embrace the principle of integration, pointing to importance of normalisation, inclusion into society, the right for children not being separated from other children or similar expressions. Moreover, many countries have taken concrete steps in de-institutionalisation and intend to continue along the same lines From this observation we may infer that the states will welcome recommendations about de-institutionalisation and community living.

5.2 Perceived limits for inclusion

But at the same time the replies indicate that certain limits for de-institutionalisation or mainstreaming are perceived. Some quotes out of the results of the questionnaire can illustrate the perceived limits.
The Scottish key policy concerning education is phrased as follows:

- The intention behind the mainstreaming duty is to establish the right of all children and young persons to be educated alongside their peers in mainstream schools *unless there are good reasons for not doing so*[2].
- However, it also specifically allows for education to be provided elsewhere, if either, *mainstream schooling is unable to meet a child's needs*, or where their *inclusion would be incompatible with the education of other children*.

Luxembourg has similar criteria: "Excluded from school is a child whose disability is so serious that he or she is *unable to follow lessons* or whose presence would *seriously disrupt the life of the school*".

The Scottish policy further states that it will always be necessary to tailor provision to the needs of the individual child, and *to make available a range of mainstream and specialist provision, including special schools*, to meet the needs of all children.
The Flemish region in Belgium holds a similar position: 'We try to provide services that are tailored to the expressed and assessed needs of disabled children and their families. A *whole range of services has been developed, on a continuum starting with assistance at home and ending with institutional care 24h a day*.The perceived limits to mainstreamed provision can further be demonstrated by *specific categories* of children who receive special services. Relevant quotes in this context are from:
The Czech Republic: "Pupils suffering from *serious mental disability*, pupils with several learning disabilities, and *autistic pupils* shall be entitled to be educated at a special basic school if they are not thus educated otherwise".

Estonia: "In Estonian welfare institutions for children and youth live in long-term care about 455 children with disabilities, who are *without parental care* or who are *orphan*". And: " …. responsibility of organising and providing social services for clients with *severe mental disorders* (including mental disability), children *without parental care* and crime victims is incumbent on the central authority. The reason for that is that the group of clients is relatively small, the services they need are very complex or newly established". And: "Specialised medical care and rehabilitation is a service aimed at increase the ability of clients with *grave disability* (or *multiple disabilities* or *unstable remission*) to cope independently and/or

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[2] This and next italics are added by the author.

preserving quality of life in the community at a generally accepted level through supporting clients in terms of medical care, rehabilitation and daily activities".

Liechtenstein: "There are no residential provisions for children with disabilities in Liechtenstein. Children and young people with *very serious or multiple disorders* and young people with *extremely conspicuous behaviour* (and in need of residential placement) cannot be taken care of within the country".

Portugal: "For some special children with *severe and profound deafness, multiple disabilities, autism* or *deaf-blind*, there are alternative forms of education offered in specialised units within ordinary schools.

Finland: "In day care disabled children are primarily integrated into the same group with non-disabled children, but day-care can also be provided in special groups for disabled children (e.g. *sign language users*, children with *speech impairments*).

Sweden: "*Deaf and hard-of-hearing children with sign language* as their first language are taught at one of the five regional state-run special schools. There is also one national special school for *deaf and hearing-impaired pupils who are also severely learning disabled*. The emphasis on teaching in sign language, and thus need for contact with other deaf children with the same method of communication, has meant that the special school has been retained".

Indication of these categories signifies possible limits to inclusion. Apparently, for the listed categories integration is least easily to achieve. This observation raises the question: How far integration (community living and mainstreaming) can be proceeded? In other words: Are there limits to integration of children with disabilities and where should they be drawn?

Obviously, this question has important repercussions for the recommendations to be formulated by the P-RR-CLCD for the member states of the Council of Europe. The dispute can be considered as a framework for recommendations by pointing to the key issues, namely: To what extend de-institutionalisation and mainstreaming should be pursued and under which conditions it might be achieved?

5.3 Two main strategies

On the whole, two strategies for de-institutionalisation can be distinguished.
The first was applied in the Scandinavian countries in the 90s. Residential institutions were closed within a period of a few years. In this way a sudden change from residential to community living could be accomplished. During its preparation it was tried to win the parents of institutionalised children for the idea of community living, and offer the former staff of the institutions a job in the community-based services.

The second strategy implies a gradual transition towards community living. Most European countries have adopted this approach. In this policy both residential and community-based provisions are maintained. By creating (new) possibilities for community and mainstream services the (parents of) disabled children are invited to choose for inclusion. Data from several countries show that this approach is successful in a number of cases: the trend shows a decrease in residential placements.

One of the most important questions for the work of the P-RR-CLCD is whether the recommendations should favour one of these strategies: (1) follow the Nordic approach by abolishing the residential institutions for long stay and replace them by a comprehensive package of community-based services or (2) follow the present approach of the other

European countries by expanding the community-based services and making them more attractive for users, but maintain certain residential facilities.

5.4 Further questions in the drafting of recommendations:

Definition of disability

Should we adopt a definition of disability that goes beyond impairments, by including environmental factors?

Explanation:
Usual definitions of disability focus on deficiencies of the persons: having impairments that impede their functioning. However, the 'social model' of disability points to the deficiencies in the environment that produce impediments for them. In the definition of one of the member states (Norway) this stand is explicitly expressed: "People with reduced functional ability do not automatically become disabled. A person is disabled when there is a gap between the individual's capabilities and the way in which society is formed or the functions required by society".

Consideration of differences between countries

How can we account for differences between member states in our formulation of recommendations and guidelines?

Explanation:
Member states differ in many respects, like available resources, tradition and legislation. Other important differences concern the funding of care provision (e.g. national health systems in the UK, Italy and the Nordic countries, and social insurance systems in Austria, France, Germany and the Netherlands), the structure of the provision (by public or private organisations who can exercise a considerable amount of influence) and the role of central and local governments. Can we formulate general recommendations that are relevant for all member states, or should we specify according to these variations?

Ideology versus pragmatism

Should we adopt an ideological approach or a pragmatic approach in issues concerning de-institutionalisation and mainstreaming?

Explanation:
The ideological standpoint highlights the right of children to live in a family, to socialise with peers, to participate in the local community etc. Integration and inclusion versus segregation are the central concepts in this approach. But others argue that mainstreaming is not always in the interest of particular disabled children (some have needs for support that would require special treatment) or in the interest of other children (e.g. in education). This might be denoted as a pragmatic position. Should we formulate ideologically based recommendations or take a more pragmatic stand?

'Degrees' in residential institutions and community-based provisions

Should we differentiate between several types of residential institutions and community-based provisions?

Explanation:
In stead of a black-and-white picture (complete separation versus integration), the available services might be conceived as a continuum, ranging from "total institutions" to community-based provisions. In between often are small-scale institutions of open centres, situated in the neighbourhoods. How can we treat this diversity in our recommendations?

And can we speak of "good" and "bad" institutions? If so, which qualities make them as good or bad?

Promoting real changes

How can we formulate our recommendations to encourage de-institutionalisation in the member states?

Explanation:
Integration and combating segregation are concepts that might just reflect "good intentions" in the policy concerning disabled people. How can we promote that they go beyond the verbal level and are put into practice in the member states?

Limits to mainstreaming

Should we recommend specialised services (outside the mainstream) for particular categories of children?

Explanation:
From the findings in the questionnaire it can be concluded that some categories of children are more difficult to integrate in mainstream settings than others. This applies in particular to children with severe intellectual disabilities, multiple disabilities, severe behaviour disorders, hearing impairments and autism. Should our recommendations differentiate between types of impairments and, if yes, which kinds of services can we recommend?

Interests of children versus interests of parents/carers

Which recommendations should we formulate for situations in which the interests of the disabled children and their parents / carers diverge?

Explanation:
In some cases parents might prefer a residential solution for their child because they are overburdened by the care for their child. In other cases the child might be better off outside the family because of overprotection, neglect or even abuse by the parents. Foster homes are a conceivable solution is those cases. Particular services for the parents constitute another one. Which recommendations can we formulate for this complicated situation in which the interests of the child and the parents conflict?

Empowerment

How does empowerment relate to de-institutionalisation and mainstreaming?

Explanation:
In several countries (parents of) disabled children can receive an allowance for care or education. These personal budgets give the service users a certain freedom of choice. The introduction of demand driven care and services is another way in respecting the needs and wishes of the people with disabilities. This might be conceived as an aspect of empowering them. But a policy that takes its departure from the needs and preferences of the disabled children and their parents does not necessarily lead to de-institutionalisation and mainstreaming. Some people might choose for specialised, segregated services. The question arises than which principle should prevail: the wishes of the client or the integration-concept.

On the collective level a similar matter appears: What if the associations of disabled people request the continuation of certain specialised, segregated services or oppose against the dismantling of residential institutions?