



Åke Johansson spent 32 years of his life in a residential institution for people with intellectual disabilities in Sweden. He reports:

“What happens to people who live like this? They become passive and to be passive entails not knowing what is going on around them and not caring about it. You take the day as it comes and you do not wonder why everything is the way it is. Everyone around you behaves the same way; they all walk around in a sort of lethargy that becomes somnambular. You do not even have to care about your own clothes. Everything is decided for you.

Eventually this environment comes to represent safety. That which is new or different causes fear. As a result, no one causes any problems; no one starts to shout, wanting to leave. The will to leave is broken down; it does not exist any more. There is no room for real life inside such walls; this is why it is not to be found there either. You do not live, you exist.”

# Included *in* Society

This publication is a result of the project “Included in Society” aiming at analyzing the conditions in and prevalence of large residential institutions for disabled people in Europe. The participating organisations and universities collected information on the living conditions in large residential institutions in 25 European countries. This is the basis for policy recommendations addressing the need for more community-based services for disabled people.

This publication is also available in French, German, Hungarian, Polish and Romanian. Summary versions of this document are available in all EU/EEA and accession country languages to favour national debates on residential services for disabled people.

[www.community-living.info](http://www.community-living.info)

Results and Recommendations  
of the European Research Initiative  
on Community-Based Residential Alternatives  
for Disabled People

EN

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Further information about the project and community-based services for disabled people can be found on the project website at:

**[www.community-living.info](http://www.community-living.info)**

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# Included *in* Society

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of the European Research Initiative  
on Community-Based Residential Alternatives  
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This project was coordinated by

Inclusion Europe  
Autism Europe  
Mental Health Europe  
The Open Society Mental Health Initiative

In cooperation with

The Tizard Centre at the University of Kent  
The European Disability Forum  
The Association for Research and Training in Europe (ARFIE)  
The European Association of Service Providers for Persons with Disabilities  
The Centre for Policy Studies of the Central European University in Budapest



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<b>Foreword by the European Commission</b>	4
<hr/>	
<b>Executive Summary</b>	6
<hr/>	
<b>Foreword</b>	8
<hr/>	
<b>I. Introduction</b>	10
1 Objectives of the project “Included in Society”	11
2 The “Included in Society” partnership	12
3 The diversity of disability	12
4 The consequences of general social developments on residential care	14
<hr/>	
<b>II. Human Rights and Principles for Positive Change</b>	18
1 Human Rights: An overview	18
2 Universality of rights and people with disabilities	19
3 Institutional care and human rights	20
4 Human Rights challenges to institutionalised care	21
5 Using Human Rights to establish principles for positive change	22
<hr/>	
<b>III. The Situation of Large Residential Institutions in Europe</b>	28
1 The number and characteristics of large residential institutions in Europe	28
2 In-depth study of institutions in four countries	38
3 Discussion of the results	54
4 A study on the legal and financial basis of residential services	56
<hr/>	
<b>IV. Goals for Community Living in Europe</b>	60
<hr/>	
<b>V. Policy Recommendations</b>	64
1 Develop policies and action plans at local, national, European and international level	64
2 Community-based services in the new member states and accession countries	67
3 Establish compulsory systems of quality monitoring and enforcement	68
4 Establish financing systems based on individual needs	69
5 A commitment to stop the building of new large residential institutions in Europe	70
6 The European Coalition for Community Living	70
<hr/>	
<b>VI. Activities of Different Actors</b>	72
1 National and regional governments	72
2 Local administration and policy	80
3 The European Union	81
4 NGOs and service providers	83
<hr/>	
<b>ANNEXES</b>	86
Study on the legal and financial basis of residential services for disabled people in Europe	86
References	94
Contact details of the participating organisations	97
<hr/>	



I welcome this important European research initiative undertaken by organisations of disabled persons to examine the situation of people with disabilities placed in large residential institutions. The results of this study can only but contribute to reinforcing the achievements of the European Year of People with Disabilities during which this project was launched with both financial and political support from the European Commission. Indeed, the European Year of People with Disabilities not only provided a unique opportunity to increase awareness of disability as an issue which concerns the whole of society. It also allowed us to move forward to tackle issues of concern to people with severe or multiple disabilities, and their families, who are the most "invisible" citizens regarding access to their human rights and satisfaction of their needs.

People with high dependency needs cannot necessarily participate actively in all areas of life, yet they still have a right to non discrimination and freedom of choice as to how and where they live, to a good quality of life and to be socially included. This is all the more so when considering children with disabilities who should be enabled to grow up within their families. Therefore we considered it necessary:

- to depend upon reliable and comparable quantitative data on the existing situation of people with disabilities in large residential institutions in the enlarged European Union;

- to collect quantitative information from as many residential institutions as possible so as to increase and consolidate knowledge about institutional characteristics;
- to determine the links between service characteristics and quality of life of the residents notably with a view to establishing whether, and if so to what extent they are culturally dependent;
- to ask representative NGOs, including human rights and user organisations, to analyse successful examples of de-institutionalisation with a view to developing political recommendations at European, national, and local levels which in turn would have the potential to lead to concrete improvements in the situation of many disabled persons across the European Union. I am pleased to note that Dr. Bengt Lindqvist, former UN Rapporteur on the UN Standard Rules for Equalisation of Opportunities for People with Disabilities contributed to the Policy work of this Study.

The study shows clearly that large residential institutions, often located in isolated places, segregate their residents from the community and from social life. Furthermore, it provides evidence of situations in which the human rights of residents in large institutions are often violated. This is unacceptable.

However, the study goes further than developing an overview of institutionalised care: the study also demonstrates that large residential institutions are not able to deliver the same access to rights and quality of life for their residents as community based-services can do. It therefore examines possibilities for, and conditions of de-institutionalisation towards alternative community-based forms of care and support. The latter would further promote the elimination of discrimination which particularly affects those people with disabilities who have high-dependency needs. This in turn would distance them from an outdated approach of service provision based on the old medical model of curing and caring.

The conclusions and suggestions for further initiatives which can be drawn from the results of the study are the following:

- reliable data regarding the situation of disabled persons, when they exist, are often difficult to compare, as common definitions and standards are lacking;
- parameters to evaluate the correlation between service provision and quality of life of the persons affected need to be developed;
- these data are necessary to define and implement an appropriate strategy to reduce the number of large institutions and increase the provision of community-based alternatives. Therefore increased efforts should be made to make such data available to policy makers, using the expertise and means of Eurostat as well as the possibilities offered within framework research programmes of the European Commission;
- the study recommendations, based on experience from pioneer countries and on expertise of professionals and associations involved in the field of disabilities to promote such community-based alternatives, will enrich the reflections carried out within the European context. Moreover, mainstreaming will contribute to fostering such an approach in all relevant European policies.

For my part, I conclude from this study that with the appropriate assistance from relevant actors, the well-being of disabled persons can be significantly enhanced. In this respect, community-based settings play a crucial role in the well-being of people with disabilities, alongside families whose role as care providers should not be a pretext for the disengagement of public authorities. The responsibilities should be shared out between all the key actors at all relevant levels, including the State which holds the primary responsibility for providing services and support.

It is clear, therefore, that there is a need to further promote and develop modern and effective strategies with regard to the supply of support systems and of community-based care services. This would create a paradigm shift in the overall vision of systems for the provision of services to people with disabilities in the enlarged European Union.

**DIRECTOR GENERAL ODILE QUINTIN**



Directorate General  
Employment and Social Affairs



# Disabled people have the right to live included in society

In the past, disabled people in Europe often had to live in large residential institutions. Disability organisations, self-help and self-advocacy organisations, point out that these settings are no longer acceptable in modern European societies. Large residential institutions segregate residents from the community and normal social life.

There have been numerous reports about large residential institutions which detail unacceptable conditions and intolerable violations of the human rights and dignity of residents. However, only some states have taken concrete steps to alter the policy of segregating disabled people from society, which, in itself, constitutes a major human rights violation.

All member states of the European Union are committed to the protection and promotion of human rights. The Union's new social policies seek to ensure that disability issues are addressed in all areas of life. In addition, EU policy is to avoid exclusion and to encourage the social integration of disabled people.

Furthermore, there are numerous international and European laws that protect human rights and fundamental freedoms. They provide protection from arbitrary detention, adequate living conditions, adequate provision of care and treatment, individualised care plans, protection from harm, the right to private and family life, and the right to privacy.

Although human rights are universal, until relatively recently, disabled people have not been seen as beneficiaries of such rights. Too little attention has been given to addressing the serious human rights abuses suffered by them. Increasingly, the potential serious human rights violations represented by the placement of disabled people into institutional care are being recognised and challenged. For example, the United States Supreme Court recently held that the unjustified segregation of individuals with 'mental disabilities' in institutions constituted discrimination.

Accordingly, the development of high quality community-based services must be founded upon the core values of equal citizenship and social inclusion. Arising from existing human rights instruments, five key principles for positive change can assist and underpin such work: respect, choice, participation, independence, as well as regional/local responsibility for disabled citizens.

The study conducted by the project "Included in Society" is the first attempt to compare institutions for disabled people in different European countries. Its findings are, out of necessity, exploratory. Nevertheless, it provides a large amount of broadly comparable data and presents a relatively clear and consistent picture.

The study about the number and characteristics of large residential institutions in 25 countries identified almost 2.500 institutions. This part of the study further revealed the lack of comparable data about institutional service provision for disabled people in Europe.

The in-depth study of residential institutions in France, Hungary, Poland and Romania showed that in many respects, large residential institutions in these four countries are similar to those that have been studied elsewhere. Residents often live lives characterised by hours of inactivity, boredom and isolation. Staff numbers are frequently too low to provide habilitation and therapy. The physical environment is relatively impersonal and does not provide the kind of privacy and homeliness that the general population expect. Contact with family, friends and community is limited. In this situation practices develop that should be unacceptable, such as keeping people in bed all day or the use of cage beds to confine people.

Observations from existing institutions visited during this project document the research results in practical terms. The eyewitness reports included in this report give direct evidence of staff practices and the general situation.



The overall picture that emerges from the research is that, on average, community-based services offer better outcomes in terms of quality of life for disabled people than do institutions. Replacement of institutions by community-based alternatives therefore provides opportunities, but does not, in itself, guarantee better outcomes – it is a necessary but not sufficient condition. The achievement of good outcomes in community-based services depends on the quality of staff support available to disabled people.

The study of the legal and financial framework of large residential institutions revealed some problems for service providers in the process of moving to community-based residential services.

In order to make it possible to achieve the vision of disabled people living as equal citizens included in society, various goals need to be established. These goals describe what needs to be achieved in the long-term. In the future, disabled people should have the same opportunities as other citizens to exercise their rights and participate fully in the society in which they live. They should have access to comprehensive, high quality community-based alternatives to institutional care. All stakeholders should be involved in establishing these services, which are designed and provided on the basis of individual needs. The principles for positive change are central to any action taken in relation to planning, providing and reviewing community-based services. Furthermore, advocacy and peer support should be ensured and promoted.

To achieve the goals for community living and the availability of comprehensive and high quality community-based services for all disabled people across Europe, the “Included in Society” project proposes six policy priorities:

- I. Develop and implement policies and action plans for the provision of community-based services that respect and promote the human rights of disabled people. In this context, it is essential to mainstream disability policy at all levels, to reinforce the UN Standard Rules and to include the issue appropriately in the UN Convention on the Rights of People with Disabilities.

- II. Provide, as a priority, community-based services for disabled people in the new member states and accession countries of the European Union.
- III. Establish compulsory systems of quality monitoring and assurance within the framework of consumer protection policies, as well as accessible complaints mechanisms for service users.
- IV. Establish financing arrangements that ensure services are provided on the basis of individual needs.
- V. Sign up to the Commitment to stop the building of new large residential institutions in Europe.
- VI. Establish the “European Coalition for Community Living” as a European monitoring and action centre for the provision of community-based services.

While the creation of community-based alternatives requires the participation of many different decision-making bodies and individuals, national governments remain responsible for providing quality services to all their citizens.

All stakeholders - disabled people, their families, service providers, disability organisations, national and local authorities, and the European Union - should work together to reach the goals and objectives in respect to the establishment of community-based alternatives to institutions in Europe. The European Union is called upon to support this process by addressing the issue of large residential institutions in its regular reports concerning Human Rights, the situation of disabled people, and social exclusion. It should also provide the means for the necessary studies as well as for exchange of policies and experience at European level in order to ensure the provision of quality community-based residential services in all European countries.

# A result of the dedicated work of many persons and organisations

A considerable number of people with disabilities live in residential institutions. Disabled people in such institutions are usually the most "invisible" citizens. There is often great ignorance about their practical living conditions and how their needs and rights can be matched with those conditions. Therefore, during its sitting of 19 December 2002, the European Parliament specifically asked for a study to be conducted to analyse the situation of people with disabilities in institutions across Europe, including the candidate countries for accession to the European Union.

When the "Included in Society" project was originally conceived as a European research initiative into the de-institutionalisation of disabled people, the objectives were set very high. The European Commission asked the project to take stock of the situation of people

with disabilities in institutions in the largest possible number of EU/EEA and Candidate Countries, within the relatively small timeframe of 15 months. It was felt that, the project should add to the understanding of how institutions responsible for the care of people with disabilities operate, by providing an overview of institutionalised care in these countries, including human rights related issues. Furthermore, the project was set the task of developing policy proposals for the purpose of changing policies in favour of community-based services.

The management partners of the project responded to this challenge. Under the leadership of Inclusion Europe, Autism Europe, Mental Health Europe and the Open Society Mental Health Initiative (formerly the OSI Mental Disability Advocacy Program), a consortium was established along with a



range of other organisations who were contracted for different responsibilities:

- The research work of the project was coordinated by The Tizard Centre at the University of Kent.
- The European Disability Forum provided policy expertise and contacts.
- The Association for Research and Training in Europe (ARFIE) was responsible for conducting the in-depth study of residential services and a literature review in France.
- The European Association of Service Providers for Persons with Disabilities (EASPD) provided the study on the legal and financial basis of residential services for disabled people in Europe.
- The Centre for Policy Studies (CPS) of the Central European University in Budapest coordinated the in-depth study of residential services and a literature review in Hungary, Poland and Romania.

This report presents the results of the work carried out by the project. It would not have been possible without the dedicated work and support of the staff of the participating organisations. Special thanks go to the Project Manager, Magali Coué, for her dedicated work, as well as to Jim Mansell and Camilla Parker for their important contributions. We would also like to thank the following persons for their knowledge and support: Maarit Aalto, Julie Beadle Brown, Sophie Beaumont, Christine Cahill, Raymond Cecotto, Jean-Louis Chapellier, Bogdan Chiritoiu, Sue Clegg, Kent Ericsson, John Evans, Henri Faivre, Geert Freyhoff, Natacha Glautier, John Henderson, Peter Kampman, Agí Kende, Andrea Krizsan, Marcell Kwasniewski, Petr Nawka, Johannes Schädler, Sylvia Tsanova, Mary van Dievel, Josée Van Remoortel, Ihor Vasylyev and Luk Zelderloo.

Liz Lynne MEP, the former UN Special Rapporteur on Disability Bengt Lindqvist, and the Commissioner on Human Rights of the Council of Europe Alvaro Gil-Robles gave us their support and encouragement. Wallis Goelen, Frank Marx and Christiane Bardoux of the Disability Unit of the European Commission provided helpful advice.

We would also like to thank the residents, staff and managers of the institutions studied in this project for their willingness to share their experience.

In the name of the managing organisations, we hope that this project will mark an important step forward in the establishment of quality community-based services for disabled people in Europe.

**Françoise Jan,**  
President of Inclusion Europe

**Donata Vivanti,**  
President of Autism Europe

**Claude Deutsch,**  
President of Mental Health Europe

**Judith Klein,**  
Director of the Open Society Mental Health Initiative

# An important European initiative for disabled people

Government policy in the past has often been to place disabled people in large residential institutions. Self-help and advocacy organizations of disabled people are voicing a widely-held opinion that these settings are no longer acceptable in modern European societies. Large residential institutions segregate residents from the community and normal social life.

There also have been numerous reports about large residential institutions which detail unacceptable conditions and intolerable violations of the human rights and dignity of residents. In spite of this, very little has been done to alter the policy of segregating disabled people from society, which in itself constitutes a major human rights violation.

All member states of the European Union have committed themselves to the protection and promotion of human rights. Its new social policies seek to ensure that disability issues are addressed in all areas of life. In addition, it is EU policy to avoid exclusion and to encourage the social integration of disabled people.

Over the past two centuries, the government policy of many countries has been to place disabled people in large institutions, often situated in remote parts of the country so that residents have little or no contact with the outside world. The individuals who have been most affected by these policies are people with intellectual disabilities, Autistic Spectrum Disorders, those enduring mental health problems and those with complex dependency needs.

Self-help and advocacy organizations of disabled people in many countries have pointed out that these settings reflect the social and economic realities of the past and are no longer acceptable in modern European societies. Large residential institutions segregate residents from the community and from normal social life. Scientific research has demonstrated that such institutions are not able to deliver the same quality of life for their residents as community-based alternatives.

Furthermore, there have been numerous reports about large residential institutions in European Union member states, which have revealed details of unacceptable conditions and intolerable violations of human rights and dignity. While such reports have sometimes led to widespread media interest in the plight of people confined in such institutions, this attention is often short-lived, and in most cases, the response of the Government of the particular country has been to either fund a renovation of the institution or to move the residents to another institution. However, it is usually the case that very little is done to alter the policy of segregating disabled people from society, which in itself, constitutes a major human rights violation.

In order to enable disabled people to live, with the necessary support, in the community and to have the same opportunities to participate



in society as everyone else, it is imperative that concrete steps are taken to shift the provision of care from closed institutions to community-based services.

## 1 Objectives of the project “Included in Society”

The purpose of the ‘Included in Society’ project is to make politicians, policy-makers and the general public aware of the rights of those disabled people who are currently segregated in large institutions and to demonstrate the need to provide alternative community-based care. Recommendations are also made on how sustainable alternative community-based services can be developed. Two key principles are that disabled people must be involved in the development of such services, and that services must be provided on the basis of individual needs.

Within the boundaries of the extremely limited timeframe of 15 months, the partners of the project have achieved the following objectives:

1. The project collected and analyzed quantitative information about almost 2.500 large residential institutions in 25 countries in Europe.
2. The project studied in detail, institutional conditions and community based alternatives in France, Hungary, Poland, and Romania, focusing on issues such as quality of care, residents’ needs and characteristics, numbers of staff as well as their allocation and characteristics, physical environment, care practices, and residents’ satisfaction. This data was used to determine the links between service characteristics and quality of life of the residents. This was complemented by a literature review in other countries.

3. The project identified human rights abuses and infringements of personal freedoms that occur inside institutions.
4. On the basis of this research, the project has developed policy recommendations at European, national and local levels.

This project has built on national initiatives, which have already existed for many years. At the European level, it marks the beginning of a European movement for de-institutionalisation and for additional community-based services for disabled people.

## 2 The “Included in Society” partnership

“Included in Society” was initiated, organised and co-financed by four major advocacy organisations in the field of disability.

- **Inclusion Europe** is the European Association of Societies of Persons with Intellectual Disabilities and their Families. This non-profit organisation campaigns for the rights and interests of people with intellectual disability and their families throughout Europe.
- **Autism Europe** is a European network of associations of parents of persons with autism all around Europe. Its main objective is to promote and protect the human rights of persons with autism and their families and help improve their lives.
- **Mental Health Europe** is a representative organisation of associations in the field of mental health, including users and carers, volunteers and professionals. Mental Health Europe is committed to the promotion of mental health, the prevention of mental distress and the protection of the human rights of users, ex-users, survivors and their families and carers.
- The **Open Society Mental Health Initiative** (formerly the OSI Mental Disability Advocacy Program) supports initiatives that seek to address the massive over institu-

tionalisation, the lack of community-based services, and general exclusion from society of people with mental health problems and/or intellectual disabilities in Central and Eastern Europe and the former Soviet Union.

The research work of the project was coordinated by the **Tizard Centre of the University of Kent**.

The following organisations supported the work of the project:

- The European Disability Forum
- The Association for Research and Training in Europe (ARFIE)
- The European Association of Service Providers for Persons with Disabilities (EASPD)
- The Centre for Policy Studies (CPS) of the Central European University in Budapest

The European Commission, DG Employment and Social Affairs, Unit for the Integration of People with Disabilities, has not only co-financed this important project, but has also contributed substantially to the content of the work and the policy recommendations.

## 3 The diversity of disability

The very concept of “disabled people” creates the misleading impression of a homogeneous group of people with similar needs and abilities. However, disabled people face a large variety of situations and every person is different. Indeed, what is the common feature of a person with autism, a person with physical disability and a person who is blind? By way of examples, brief descriptions of the particular issues affecting different groups of disabled people are set out below.

- Persons with intellectual disabilities

Intellectual disability is a condition where people have significant difficulties in learning and understanding due to an incomplete development of intelligence. Their skills in areas such as cognition, language, motor and social abilities can be permanently impaired.



Most needs of people with intellectual disabilities are the same as other people: social contact, security, adequate housing, education, work, etc. Some might need additional education, but can live independently with some support. Others need life-long educational and social support. All people with intellectual disabilities are able to express their needs and wishes; they do not, however, always express themselves in a verbal form.

- People with mental health problems

One in four people develop mental health problems at some stage in their life. Also referred to as 'mental illness', mental health problems affect the way a person feels or behaves. For example a person with a diagnosis of depression may experience sadness, decreased energy, loss of interest, sleep and appetite disturbance, feelings of guilt and hopelessness. Suicide remains one of the common outcomes of depression. A person with a diagnosis of schizophrenia may experience profound disruptions in thinking and perception, including psychotic episodes and hallucinations, fear and bewilderment.

Because of the complex causes of mental health problems, a diversified and combined treatment is often proposed, such as medication, psychotherapy, family therapy, etc. Treatment takes place in different settings: psychiatric hospitals, psychiatric wards in general hospitals, community mental health services, or private psychiatrists or psychotherapists. It is important that treatment in hospitals is limited to the shortest possible period of time. Self-help groups can also be of great help (enabling individuals to share their feelings and experiences).

- Physically disabled people

Historically, physically disabled people have very often lived in institutions. For many, this is still the case. It is a tragedy that even in 2004, there are many young disabled people who acquire a disability either through injury or disease who end up in an institution. This is usually because their homes are not adequately accessible and they are not



provided with the appropriate support and assistance that they need in order to live in the community.

Towards the end of the 1970's disabled people in western European countries started to campaign for 'independent living', namely measures which would assist disabled people to move out of the institutions in to their own homes in the community. In those countries, independent living has transformed disabled peoples' lives by giving them more control and choice, improving the quality of their lives and by providing them with real citizenship.

- People with complex dependency needs

People with complex dependency needs are usually people with intellectual disabilities combined with other disabilities or chronic diseases. Among this group are also people with autism, people with intellectual disabilities who also have mental health problems, people with head injuries and people with rare diseases leading to increasing and severe disabilities.



People with complex dependency needs require care, education and multi-disciplinary support. Inclusion of these children and adults in ordinary life can create frustration and regression if the necessary support is not fully available. However, adults with complex dependency needs can live independently or in a family if substantial technical equipment and/or the support of a multidisciplinary team of professionals is available.

- Persons with Autistic Spectrum Disorders (ASD)

Autism is the core condition of a spectrum of disorders of brain development and functioning which are linked to difficulties in social interaction and communication, leading to a rigid pattern of behaviour. The majority of people with ASD have learning disabilities, and many tend to develop challenging behaviours like self-mutilation or aggressiveness, which may lead to physical restraint or may require pharmacological intervention. People with ASD require a range of specific, sophisticated, individually tailored care, appropriate and meaningful education, life-long training and ongoing supervision.

Like any other human being, a person with ASD wishes to live a full, worthwhile life within the possibilities of their own, unique capabilities. A person with ASD also wishes to benefit from opportunities to achieve independence and a good quality of life in terms of physical, emotional, social and material well-being and freedom from abuse or exploitation. These needs are best met in community-based services, in an environment that fosters communication and is adapted to their behaviour and problems with social interaction.

In addition to considering the needs of individuals with particular disabilities, the following additional characteristics must be taken into account.

- Ageing and older people with disability

As with the general population, the life expectancy of disabled people is constantly increasing. For disabled people, this might

mean that their disabilities become more severe, or that age-related problems and disabilities add to the problems that they experience in their daily life. Furthermore, the risk of social isolation may increase as parents die and other relatives have less contact.

Therefore, solutions are necessary for the creation of support services for disabled people who can no longer be economically active. These services should be integrated with other services for older people whilst providing any additional support that disabled people might need.

- Disabled people from ethnic minorities

In many European countries there are quite large ethnic or linguistic minorities. Disabled people from such communities often find that services are either not available in their language or do not respect their culture or religion. Disabled people from a Jewish background or with Islamic faith, for example, find it difficult to access services that enable them to participate in the cultural or religious life of their community. Without such possibilities, opportunities for social contact are also likely to decrease resulting in more social exclusion and segregation.

As the above examples illustrate, people who share similar disabilities will nonetheless have different needs and abilities. Thus, it is essential that each and every disabled person is provided with the support and assistance that meet that particular person's needs.

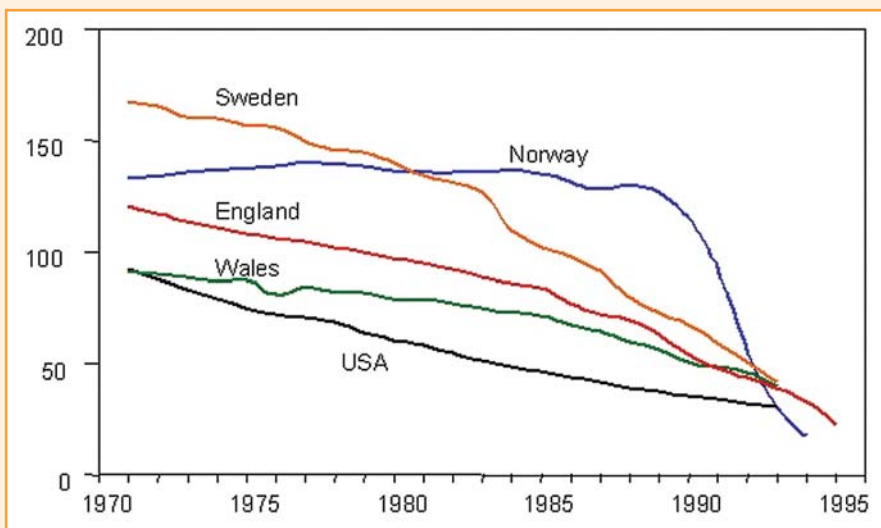
#### **4 The consequences of general social developments on residential care**

When considering the current situation for residents of institutions, it is necessary to consider the implications of general social developments and attitudes towards disabled people. The three issues with the most important implications for systems of residential care for disabled people are social attitudes, budget limitations and demographic aspects.

## Deinstitutionalisation in Scandinavia, the United States and Britain<sup>1</sup>

The number of places in institutions for people with intellectual disabilities in Sweden, Norway, the United States, England and Wales has declined over the last 25 years. The numbers have been converted to rates per 100,000 total population in order to permit comparisons.

### Places per 100,000 total population in institutions



In the United States the picture is of steady substantial decline over the whole period, slightly less steep in the later years. In Sweden, England and Wales the decline during the 1970s increases during the 1980s and 1990s. In Norway the onset of deinstitutionalisation is much later, although this is in due to the fact that many of the institutions were small and would be called group homes in other countries. The different rates of institutional provision across the different countries must be interpreted with caution, since they may to some extent reflect a different balance between types of service rather than different overall levels of provision of residential care. Nevertheless, it is plausible that Sweden and Norway, with a long tradition of investment in public services, should provide the most services, and that England and Wales, where institutional care is provided through a National Health Service, should also provide more services than the United States, with its commitment to free enterprise and its caution about public services.

<sup>1</sup> Adapted from Mansell and Ericsson, 1996

i Social attitudes towards residential services

Institutions for disabled people were built with good intentions: the idea was that people with special needs would have those needs met more effectively if they were all gathered in the same place. However, altruism was not always the only motivation: through institutionalisation, society no longer needed to concern itself with disabled people. In many cases, disabled people were segregated from society so effectively that their very existence was completely forgotten by many non-disabled people in the 'outside world'.

Thus, institutional care and segregation have left a legacy in the minds and attitudes of people that must be overcome. Today, disabled people are still not usually considered to be a normal part of society, nor is it considered normal to interact with them. Fortunately, there are many campaigns which seek to address negative social attitudes in society by showing that, although in need of support in some areas of life, disabled people are citizens who contribute to society. These positive approaches need to be further developed in the future.

ii The need for increased financial efficiency

Budgetary considerations have often been used to legitimise the institutionalisation of disabled people. It has been argued that institutional care would be more cost effective and less expensive for society than community-based alternatives. This argument has won support in situations of economic stagnation and reduced social budgets.

Whilst it is not only unacceptable to violate fundamental human rights of citizens because of budgetary considerations, many studies have also demonstrated that the financial argument for institutions is of very limited validity. As this publication will highlight again, community-based services tend to cost approximately the same as institutional care. However, the quality of life offered by community-based services tends to be much better. Furthermore, when the structural costs linked to the management of institutions are taken into account, it appears that in some cases, institutions actually cost more than community-based services.



### iii Demographic developments

The population of disabled people is subject to the same demographic developments as the whole of society. However, the effects of better medical care lead to a much greater increase in life expectancy than in the general population. For example, the life expectancy of people with Down's Syndrome has increased from 9 years in 1929 to 47 years in 1986, and, at present to 60 years.

An exceptionally strong increase in life expectancy can be anticipated in the population of large residential institutions in Central and Eastern European countries.

Extremely poor medical and hygienic conditions have, in the past led to horrifying death rates. This situation will hopefully improve dramatically in the coming years.

However, these positive developments in the make-up of the disabled population are very rarely – if at all – reflected in the service planning of governments and service providers. In the future, more disabled people will need residential services for a longer time in their lives. It is thus not only more service-locations that are required, but also new structures and approaches to services. For example, there are, as yet, very few responses to the specific needs of ageing and older people with disabilities.

### **Supported Living in Bucharest**

This is a service that provides accommodation for twelve people with mental health problems, as well as support and counselling in order to develop their coping-skills and ability to deal with daily domestic activities. The supported accommodation offered by the Estuar Foundation comprises four ordinary flats in different areas of Bucharest. Each of the flats can accommodate three tenants, all tenants have individual bedrooms with own keys. The flats have been fully furnished by Estuar, creating a normal domestic environment. Each house respects standards of hygiene and comfort.

Depending on each tenant's needs and on the particular character of each house, selected and trained Estuar support workers offer their competence and abilities to listen to the tenants and to help them with social activities and domestic tasks. The tenants are permanently supported in their learning processes and in their efforts to assume responsibility for personal decisions, searching for a job, or rebuilding a family life etc.

Further information: [www.estuar.org](http://www.estuar.org), [estuar@mail.dntcj.ro](mailto:estuar@mail.dntcj.ro), [estuar@dnt.ro](mailto:estuar@dnt.ro)

# All services for disabled people must be based on respect for Human Rights and Fundamental Freedoms

There are numerous international and European laws that protect human rights and fundamental freedoms. They provide for protection from arbitrary detention, adequate living conditions, adequate provision of care and treatment, individualised care plans, protection from harm, the right to private and family life, and the right to privacy.

Although human rights are universal, until relatively recently disabled people have not been seen as beneficiaries of such rights. Too little attention has been given to addressing the serious human rights abuses suffered by disabled people.

Increasingly, the potential serious human rights violations represented by the placement of disabled people into institutional care are being recognised and challenged. The United States Supreme Court recently held that the unjustified segregation of individuals with 'mental disabilities' in institutions constituted discrimination.

The development of high quality community-based services must be founded upon the core values of equal citizenship and social inclusion. Accordingly, five key principles arising from existing human rights instruments are suggested in order to assist and underpin such work. These principles for positive change are as follows: respect, choice, participation, independence, and regional/local responsibility for disabled citizens.

### 1 Human Rights: An overview

In 1948, the Universal Declaration of Human Rights (UDHR) was adopted by the United Nations (UN). This was the first time that such a range of rights had been documented. These rights fall into two broad categories:

- Civil and political rights: including the rights to liberty, to vote, to private and family life and to freedom from torture, inhuman and degrading treatment or punishment.
- Economic, social and cultural rights: including the rights to work, to education and to the highest attainable standard of physical and mental health.

Although not legally binding, the UDHR has inspired numerous and wide-ranging international instruments of human rights, including two legally binding UN treaties: the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR).

Four other core UN human rights treaties are the Convention on the Elimination of All Forms of Racial Discrimination (1965), the Convention on the Elimination of All Forms of Discrimination against Women (1979), the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (1984) and the Convention on the Rights of the Child (1989).

In Europe, the key, legally binding human rights treaties are the European Convention on Human Rights (1950), ('the ECHR') and the European Social Charter, 1961 (revised 1996). The ECHR sets out a range of civil and political rights while the European Social Charter addresses economic, social and cultural rights. The European Convention on the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, 1987 is

also significant. It saw the establishment of the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (the CPT), which, through inspection visits, examines *'the treatment of all categories of persons deprived of their liberty by a public authority, including persons with mental health problems'*. The CPT has published a report in which it draws together its views on the manner in which persons deprived of their liberty ought to be treated (referred to as the CPT Standards)<sup>2</sup>.

The European Union Charter of Fundamental Rights (2000) sets out a range of civil, political, economic and social rights such as the right to life, to privacy, to freedom of expression, to equality and to freedom from discrimination. Although not yet legally binding, the status of the charter will change when the European Constitution comes into force (on ratification by the Member States). It then will provide a means for Community action to prohibit discrimination on the grounds of disability (art. 21) and provide justification for positive developments on behalf of disabled persons as a means of ensuring equal opportunities (art. 26).

Article 13 of the Treaty of Amsterdam authorises the EU to take action to combat discrimination based on a range of grounds, including disability. For example, the EU Directive on Equal Treatment in Employment prohibits discrimination in the areas of employment and training on a number of grounds, including disability.

As yet, there is no international human rights treaty specific to disability, although the UN is currently considering this<sup>3</sup>. However, the UN has adopted various declarations that address the human rights of people with disabilities, the most significant being the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities ('the Standard Rules') which seek to ensure that all disabled people, *'as members of their societies, may exercise the same rights and obligations as others'*. It will be important to sustain and reinforce the Standard Rules as a benchmark for services for disabled people.

Another example of a declaration addressing the rights of residents of institutions is the Principles for the Protection of Persons with Mental Illness (the MI Principles). Adopted by the UN in 1991, the MI Principles provide guidance on areas such as the procedures for involuntary admission to mental health care facilities and standards of care. Although referring to 'people with mental illness' the scope of the MI Principles is much wider as they include all persons admitted into a mental health facility.

Although not legally binding, the Standard Rules and MI Principles can provide a useful guide on the implementation and interpretation of the legally binding treaties.

## 2 Universality of rights and people with disabilities

Although human rights are universal – applying to every human being, until relatively recently, disabled people have not generally been seen as beneficiaries of such rights. As a result, too little attention has been given to addressing the serious human rights abuses suffered by them. This has been referred to as the 'invisibility' of disabled people, in that the values underpinning human rights have not been applied, or are applied differently, to disabled people:

*'This is a legacy of the past, when people with disabilities were often virtually invisible citizens of many societies. They have been marginalized in nearly all cultures throughout history. A common reaction (on the part of both the general public and policy makers) was either pity or revulsion...*

*...Invisibility has also led to a tendency to disregard the normal legal protections for the advancement of human freedom that we take for granted. It is as though existing legal protections are either not applied or applied with less vigour in the case of persons with disabilities.<sup>4</sup>*

<sup>2</sup> European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, 2001

<sup>3</sup> [www.unchr.ch/disability/study.htm](http://www.unchr.ch/disability/study.htm)

<sup>4</sup> Quinn & Degener, 2002, 23





### 3 Institutional care and human rights

The social isolation of many disabled people across Europe exacerbates their 'invisibility'. Despite the shift towards a human rights perspective of disability over the last decade or so - for example the UN Standard Rules playing an important role in raising awareness of the human rights of people with disabilities - many individuals who have been institutionalised remain 'marginalized and forgotten'<sup>5</sup>.

In Central and Eastern Europe, government policies are still focused on placing people with mental health problems and/or intellectual disabilities in large remote institutions while those individuals who have not been institutionalised are also likely to be socially excluded due to the lack of available services in the community. In addition, social exclusion of disabled people who are living in the community, is often compounded by their relatives wishing to protect them from abuse and/or to avoid bringing shame on the family<sup>6</sup>.

Concerns about human rights abuses within institutions were a major factor contributing to the shift in policy from institutional care to the provision of community-based services in many western European countries .

Over the past ten years, reports have highlighted serious human rights abuses within institutions in Eastern and Central Europe<sup>7</sup>. The reports identify a range of human rights violations within institutions for people with mental health problems and intellectual disabilities (often described as 'people with mental disabilities'). For example, individuals are involuntarily placed in institutions, and have no right to an independent review of their detention. There is inadequate food, heating and/or clothing for the residents, the buildings are poorly maintained, often with unhygienic sanitation; residents have to live in large and overcrowded dormitories where there are little or no facilities to keep personal possessions safe; there are little or no rehabilitative or therapeutic activities, in fact there is very little to do at all.

<sup>5</sup> *ibid*, 24

<sup>6</sup> Klein and Parker, 2003, 16

<sup>7</sup> See for example Mental Disability Rights International, 1997; Mental Disability Advocacy Centre, 2003.



The use of unmodified ECT<sup>8</sup> (electroconvulsive therapy) and the use of cage beds<sup>9</sup> were also noted in some institutions.

Thus, these reports show serious violations of the human rights of the residents. For example, they highlight the failure to comply with the following standards:

- **Protection from arbitrary detention:** A person's right to liberty may only be restricted in limited circumstances and in accordance with a procedure prescribed by law. (See for example Article 9 ICCPR and Article 5 ECHR.)
- **Adequate living conditions:** The CPT Standards state *'the provision of certain basic necessities of life must always be guaranteed in institutions where the State has persons under its care and/or custody. These include adequate food, heating, clothing as well as – in health establishments – appropriate medication'*.
- **Adequate provision of care and treatment:** *'All persons who are deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person.'* (See Article 10, ICCPR).
- **Individualised care plans:** Both the UN Principles for the Protection of Persons with Mental Illness and the CPT emphasize that treatment should be based on an individualised approach, so that individuals should have their own treatment plan.
- **Protection from harm:** appropriate procedures must be in place to protect patients from other patients whose actions may cause them harm. There should also be adequate numbers of staff present at all times (the CPT Standards). Physical restraint should not be used unless this is the only means available to prevent harm to the person or others and when used, it must be carried out in accordance with approved policies or procedures and for the minimum time necessary.

- **The right to private and family life:** This right can cover a wide range of issues which will be of crucial importance to residents such as receiving and sending correspondence, the provision of single sex washing facilities, access to health and personal records, the administration of medication and contact with family and friends. (See article 8 ECHR and article 17 ICCPR which both prohibit the arbitrary interference of individuals' private and family life.)
- **Privacy:** The CPT Standards highlight the importance of creating a 'positive therapeutic environment'. This will involve not only providing sufficient living space per patient and maintaining the state of repair and hygiene requirements of the premises, but also ensuring respect for the privacy and dignity of patients. Thus patients should be allowed to keep their personal belongings and should be provided with a lockable space in which to keep these.
- **Contact with family:** Many institutions are situated in remote areas and residents lose contact with their families and local communities. The CPT standards state that patients should be able to send and receive correspondence, have access to a telephone and receive visits from family and friends.

#### 4 Human Rights challenges to institutionalised care

Increasingly, the potential serious human rights violations represented by the placement of disabled people into institutional care are recognised and challenged. In their report to the UN on 'Human Rights and Disability', Quinn and Degener suggest that the institutionalisation of disabled people may also amount to inhuman and degrading treatment. In their view: *"Persons with mental disabilities or multiple or profound physical disabilities are particularly at risk. However well regulated*

<sup>8</sup> Where ECT is given without the use of anaesthetic or muscle relaxant

<sup>9</sup> The glossary of the Mental Disability Advocacy Center's report *'Cage Beds: Inhuman and Degrading Treatment or Punishment in Four EU Accession Countries'* describes cage beds: *'A bed with a cage placed on top of it to enclose the person within the confines of the bed. Often, a distinction is made between cage beds, constructed only of metal bars, and net beds, constructed of metal frames and netting. Since the material with which it is constructed is of secondary importance, MDAC refers to both as cage beds'*

*institutions may look on paper, the regulations may not be applied in practice. Standards of care and treatment in institutions may fall short of what is required to respect the value of human dignity and autonomy. In the past, the rights of these marginalized and forgotten groups have not been championed either from outside the system (by NGOs) or from within, although there has been a palpable change in recent times. If society lived up to its aim of achieving an independent life for all, many such institutions would not exist.”<sup>10</sup>*

A recent decision by the United States Supreme Court in *Olmstead v LC* (1999) provides support for challenging policies focused on placing disabled people in institutions. The Court held that the unjustified segregation of individuals with ‘mental disabilities’ constituted discrimination under the Americans with Disabilities Act (anti-discrimination legislation). This was because the Court considered that institutionalisation required people with mental disabilities to relinquish participation in community life in order to receive the required mental health treatment whereas people without mental disabilities could receive the medical treatment they need ‘without a similar sacrifice’. Furthermore, the actual confinement in an institution perpetrates unwarranted assumptions that the individual is incapable of participating in community life<sup>11</sup>.

It is possible that a similar argument could be pursued before the European Court of Human Rights. (Individuals who consider that their rights under the ECHR have been breached may pursue a complaint to the European Court of Human Rights.) It is argued, in the light of this case, that where government policies bias funding towards institutional care for disabled people, this could amount to a violation of Article 8 (respect for private and family life) in combination with Article 14 (freedom from discrimination in relation to the rights under the ECHR).<sup>12</sup>

## 5 Using Human Rights to establish principles for positive change

The suggested principles set out below seek to assist the development of community based services and are based upon two core values:

1. **Equal Citizenship:** disabled people are equal citizens with the same rights as everybody else. These rights include the right to vote and to marry, the right to equal access to health care and equal opportunities for education and employment.
2. **Social Inclusion:** the ultimate goal must be to ensure that people with disabilities have choice in their daily lives, have real opportunities to be independent and participate fully in their communities. Any facility that is established only for people with disabilities and is set apart from the rest of the community segregates and excludes them.

Thus, the following key principles should underpin all efforts to develop high-quality community based alternatives and ensure that the protection and promotion of the rights of people with disabilities:

### Respect

Individuals must be given the opportunity to exercise their rights, express their views, to be listened to and to be treated without discrimination on the basis of their gender, sexual orientation, age, race, disability or other status. Services should be tailored to meet individual needs, not the needs of the system and should be based on an individually prescribed plan which is discussed with the person receiving the services, and is regularly reviewed and revised as necessary.

### Choice

People should have the right to make choices about their lives, such as where they live, with whom they associate, with whom they wish to develop friendships and other relationships,

<sup>10</sup> Ibid 24

<sup>11</sup> *Olmstead v LC*, 527 US 581 (1999)

<sup>12</sup> Clements and Read, 2003, 67



and the type of services they use. If individuals have difficulties making decisions, they should be given as much support and assistance as possible to make choices for themselves and express their preferences. In such circumstances, the views of the person's family or others who provide support to that person should be sought and taken into account. When decisions are being made on a person's behalf, the guiding principle is that such decisions must be made in the person's best interest and in accordance with the principle of the least restrictive alternative.

### **Participation**

In order to ensure full and equal participation, disabled people must have access to a range of services including education, housing, employment, leisure and cultural activities. Individuals who use services, their families and others who provide support must have the opportunity to participate fully in the development, monitoring and review of such services.

### **Independence**

People should be given the opportunity to live as independently as possible, with the support and assistance that enables them to do so. This means that services must be responsive to each individual's needs, and must seek to reduce the barriers that the

person faces in achieving independence. (For example, ensuring that physically accessible housing is available for wheelchair users, providing information in 'Easy to Read' text for people with intellectual disabilities, assisting a person who has had mental health problems to seek re-employment). The least restrictive alternative must always be the guiding principle in determining the support and assistance that is to be provided.

### **Regional/local responsibility for disabled citizens**

Adequate residential services can only be created when existing social contacts are maintained and inclusion in community life is supported. This implies that residential services should care for people from the region or locality where they are located and not for disabled people whose place of origin is far away.

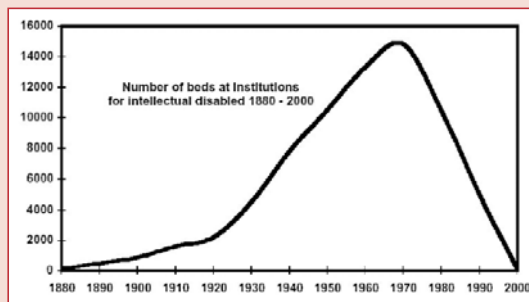
This leads to the principle that local authorities and service providers should accept the responsibility for providing quality services for people originating from their locality or region.

## Sweden: The End of an Era<sup>13</sup>

In Sweden, the term institution refers to one or more houses that are separated from their surroundings, in which many people live together, divided into different units. Institutions for persons with intellectual disabilities are called boarding schools, residential homes or hospitals.

The graphic below shows the number of intellectually disabled persons living in institutions in Sweden between 1880 and 2000. The time spent in an institution could be anywhere from a few years to a whole lifetime. Altogether, 100 000 people are estimated to have lived in institutions.

Sweden used to have two types of institutions for children with intellectual disabilities: boarding schools and residential homes for children and young people. The boarding schools were replaced with special classes at ordinary schools. This way, many children



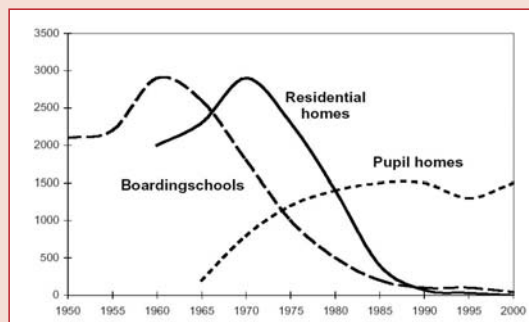
could live at home with their families, while others, who still lived far away from their schools, were obliged to live at pupil homes located in the same area as their schools.

The residential homes for children and young people could be closed gradually, as parents were given personal and financial support, the right to free day-care and pre-

school as well as support from local groups of experts, so called 'habilitation' teams. In addition, families were given the right to short-term respite from the care of the child (usually a few days at a time or a week per month) or to have temporary support-workers in the home (usually a few hours every week). In cases when parents were unable to care for their child in the home, the right to residence in a group home for four children was introduced. These group homes were based in the ordinary community and were open all the time, including weekends,

For profoundly disabled children over the age of seven, an additional right was stipulated that gave them access to special education in training schools. At its highest level, the number of intellectually disabled children and young people in institutional care in Sweden was is 5.000 people.

Today, we do not have any institutions. Out of 19.000 children and young people who receive special education, 1.400 live in pupil homes and a couple of hundred in foster homes. Out of 1.500 intellectually disabled children who are below school age, only 40 do not live with their families. There are, in addition,



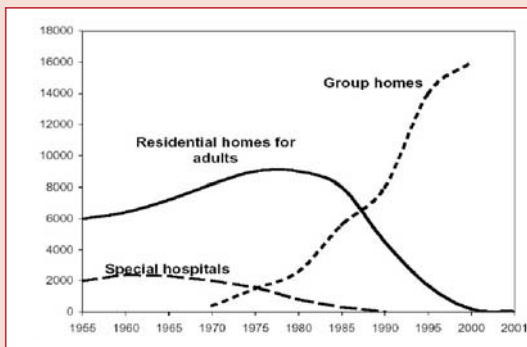
<sup>13</sup> Extracts from: Grunewald, 2003.

some smaller anthroposophic homes and three special schools for children and young people with intellectual disabilities. These schools accommodate those who, besides their intellectual disabilities, are deaf or blind or who have profound speech handicaps, including autism. (i.e. complex disabilities)

As a result, we have today, a whole new generation of disabled children and young people who are more emotionally mature and aware, as well as a new generation of parents, who are familiar with their children's needs and the obligations of society.

Did this movement from institutions for children and young people to pupil homes take place without any conflicts? On the whole, yes! Most of the protests came, understandably enough, from the staff. During the initial phase, parents of children in residential homes were sometimes sceptical as well, but they changed their minds when they saw the advantages with pupil homes. The county councils, who owned most of the institutions and who were responsible for the pupil homes and special education, accepted the new system. In the long run it was cheaper for them and it was better for the children and their parents.

For adults, the number of available care units at residential homes and special hospitals in Sweden increased during the 1960s and 70s, so that all adults with intellectual disabilities who required care could be accommodated. By the end of this period, there were around 125 institutions, one third of which were private.



The special hospitals were closed as the need for them diminished and the residents were transferred to residential homes. The residential homes were then, gradually replaced by group homes. The number of group homes increased during the 1970s. At this time, a large number of activity centres were opened. Approximately half of those people who moved into the group homes came from their parents'

homes and the other half came from residential homes. Later on, those who had profound disabilities could move to group homes as well. In 1985, the parliament proclaimed that all remaining residential homes should be closed by way of not admitting any new residents. This proved to be drastic, but well founded, decision!

That same year, the parliament decided that provision for group homes should be included in the state-issued loans that were given to ordinary homes. This was given on the condition that each person was given his or her own apartment that was no less than 40 square meters, as a part of the group home. This decision was very important. At last, people with disabilities were given the chance to live like ordinary citizens. This also included those with very profound handicaps.

Today, 60 % of all adults with intellectual disabilities live in group homes, 20 % live independently and 20 % live with their parents or other relatives. The group homes are located in apartment buildings, row houses and single-family houses. An alternative type

of housing consists of a number of apartments close to each other in the same apartment building, with one apartment set aside for the staff and as a communal meeting-place for the residents. Every year, a considerable number of people with intellectual disabilities move from group homes to apartments nearby, due to the developments in social and practical skills that they have made. No one should have to be more dependent than is necessary! By moving to an apartment nearby, the person is able to keep in touch with friends and staff.

The loneliness that many feared would occur as a consequence of inclusive living never became reality. However, it is necessary for staff to encourage and support the individual in choosing activities, participation in courses, etc. Naturally, those who possess limited abilities need support in order to experience and participate in different activities. In addition, youth leaders who organise leisure activities are necessary. As it turns out, many people with intellectual disabilities possess great skills in making new friends and acquaintances. It is striking, the way many people with disabilities are able to, and enjoy, moving freely (rambling means countryside walking, e.g. with a rucksack) in their community. Many people with intellectual disabilities choose to join different organisations or clubs.

A large number of studies have been done on peoples' experiences of living in a group home as an adult. These studies verify the advantages of this type of living compared to living in an institution.

50-80 % of the relatives of people with intellectual disabilities were against the closing of the institutions. They were afraid of the prejudice that their adult children would encounter, and feared that they would not be able to handle traffic, that they would be lonely, that their new homes would be under-staffed etc. Fortunately, none of these things have occurred. In follow-up studies, the number of satisfied relatives stands at around 80 %.

Studies have shown that those living in inclusive homes were given care that was more focused on the individual, that they felt safer and needed less medication. Aggressive and self-destructive behaviour decreased drastically. Those persons who had the most severe disabilities improved the most, in relation to their disabilities. The staff gained more influence over their own work, they had less set routines and more freedom to take their own initiatives.

## Parents' School – Lifelong Learning for Mental Health

This is a project aimed at parents of children with mental health problems, carers, and friends of people with mental health problems. The Estuar Foundation in Romania created a manual for parents and trained parents in mental health management in order for them to train other parents in similar situations. The parents meet on a monthly basis in every Community Centre to discuss their problems, share experiences and support each other.

The aim of the project is to help parents of children with mental health problems to develop their own solutions, to make informed decisions and to reduce the intensity of the burden of care. The objectives are:

1. To create a training pack and a European model of good practice in mental health education for parents of children with mental health problems.
2. To inspire interest in lifelong in order to best help those parents and their children.
3. To develop information, guidance and counselling services for parents in line with European standards.
4. To create a "forum" to review and develop best practice materials in mental health education for parents of children with mental health problems.

The parents get support and information, thus helping both children and parents in improving relationships and creating effective methods of communication. The parents also have a good environment to receive help and support. The information provided to the parents during this project will help them to create independent self-help groups.

Further information: [www.estuar.org](http://www.estuar.org), [estuar@mail.dntcj.ro](mailto:estuar@mail.dntcj.ro), [estuar@dnt.ro](mailto:estuar@dnt.ro)



## Large residential institutions and their effects are still prevalent in many European countries

This study is the first attempt to compare institutions for disabled people in different European countries.

Its findings are, out of necessity, exploratory. Nevertheless, it provides a large amount of broadly comparable data and presents a relatively clear and consistent picture.

The study about the number and characteristics of large residential institutions in 25 countries identified almost 2.500 institutions. This part of the study further revealed the lack of comparable data about institutional service provision for disabled people in Europe.

The in-depth study of residential institutions in France, Hungary, Poland and Romania showed that, in many respects, large residential institutions in these four countries are similar to those that have been studied elsewhere. Residents often live lives characterised by hours of inactivity, boredom and isolation. Staff numbers are frequently too low to provide rehabilitation and therapy. The physical environment is relatively impersonal and does not provide the kind of privacy and homeliness that the general population expect. Contact with family, friends and community is limited. In this situation practices develop that should be unacceptable, such as keeping people in bed all day or the use of cage beds to confine people.

The study of the legal and financial framework of large residential institutions revealed some problems for service providers to move to community-based residential services.

The project “Included in Society” included two empirical studies. The first was a study of the number of institutions in Europe and was carried out by all the project partners and their networks. The second was an in-depth study of institutions in four countries, carried out by the Tizard Centre of the University of Kent, the Centre for Policy Studies at the Central European University and the Association for Research and Training on Integration in Europe (ARFIE).

### 1 The number and characteristics of large residential institutions in Europe

The aim of this part of the project was to identify as many large residential institutions as possible, in order to provide a baseline against which future service development could be judged.

Comparable information about the number of institutions and their characteristics was not readily available in most countries in Europe. Therefore, project partners used their own networks to input data into a web-based template and each of the institutions recorded on this website was invited to complete a second, more detailed template. This proved an extremely challenging task for several reasons:

- *Difficulties of separating large institutions from other services.* Official sources in certain countries do not necessarily identify large residential institutions separately from other kinds of services. For example, in some countries service-providing organisations are identified, but not details of the kind of services they provide, so that large and small care settings may be counted together.



- *Split responsibilities within countries.* Mental health services, in particular, are often the responsibility of health ministries whereas services for disabled people may be the responsibility of social ministries. This makes it more difficult to secure comprehensive information.
- *Difficulties of identifying institutions.* In some countries, published data are available on the number of residential places, but these do not list the institutions providing them; elsewhere, lists were available but not the number of places provided.
- *The contested definition of 'institution'.* Not everyone agrees that large residential institutions are a bad thing. Some institutions and their representative organisations refused to provide information, because they felt that the term 'institution' had pejorative overtones and they did not wish to be associated with it. Since the project depended on institutions to provide information this was an important limiting factor.
- *Problems defining residential institutions.* In mental health services in particular, organisations may define themselves as providing short-term treatment even though they have residents who live there for many years and who have nowhere else to go. Similarly, services may not differentiate clearly by age or by disability, leading to difficulties identifying institutions to be included in the study.

In the short time available for this study, there was substantial progress in compiling this information. Table 1 shows, for each country, the number of institutions for whom an entry in the database was recorded, the number of institutions for whom data on the number of residents was available, the number of people served by these institutions and the mean number of residents per institution.

**Table 1: Number of institutions and residents<sup>14</sup>**

Country	Total number of database entries	Number of institutions for which resident numbers available	Number of residents	Number of residents	
				mean	range
Austria	8	5	417	83	37-171
Belgium	107	22	1,711	78	31-310
Bulgaria	33	33	4,424	134	101-230
Cyprus	3	2	75	38	37-38
Czech Republic	238	41	3,985	97	32-300
Denmark	0	0			
Estonia	16	2	83	42	34-49
Finland	102	85	8,407	99	31-461
France	81	69	3,454	50	31-140
Germany	132	70	15,575	223	32-4,200
Greece	16	3	589	196	35-454
Hungary	113	108	16,675	154	34-400
Iceland	1	1	84		
Ireland	56	10	995	100	33-187
Italy	87	75	5,849	78	31-360
Latvia	29	29	4,130	142	33-313
Lithuania	21	4	331	83	35-160
Luxembourg	34	2	201	101	57-144
Malta	2	1	563		
Netherlands	14	14	12,113	865	118-5,700
Norway	0	0			
Poland	433	407	46,654	115	32-750
Portugal	62	4	334	84	42-120
Romania	215	148	20,880	141	32-537
Slovakia	39	28	2,651	95	31-311
Slovenia	9	9	1,869	208	50-628
Spain	42	15	2,171	145	32-1,416
Sweden	0	0			
UK	461	399	20,654	52	31-444
<b>Total</b>	<b>2,354</b>	<b>1,586</b>	<b>174,874</b>	<b>110</b>	<b>31-5,700</b>

Comparing this information with what is known from other studies reveals an uneven picture. Table 2 shows information from a range of studies and reports about the number of institutions or the number of people in institutions of various types in Europe. These data are of different ages (ranging from 1989 onwards) and different levels of comprehensiveness. They indicate how patchy and out of date information is across

the continent. They do suggest, however, that some countries are markedly under-represented in the database assembled in this project. For example, Germany is estimated to have 55,000 people in mental health institutions<sup>15</sup> but under 16,000 with any disability were identified in this project; Spain had just over 11,500 places in institutions in 1991<sup>16</sup> but only 2,171 people (18.9%) were identified in this project. In contrast, two

<sup>14</sup> Information for Latvia from: Inclusion Europe, Rupju berns and Saule, 2004.

Information for Bulgaria from Inclusion Europe and the Bulgarian Association for Persons with Intellectual Disability, 2002.

<sup>15</sup> World Health Organisation, 2001.

<sup>16</sup> European Intellectual Disability Research Network, 2003.

studies<sup>17</sup> suggest that Poland might have about 50,000 people with intellectual disabilities or mental health problems in institutional care; this project obtained details

of institutions serving over 46,500 people. In the UK, it was possible to obtain the entire national database of social care institutions.

**Table 2: Indicators of numbers of people living in institutions<sup>18</sup>**

Country	Number of institutions	Number of residents	Rate per 1000 total population
Austria		5,000 <i>MH</i> 6,102 <i>ID</i>	0.77 <i>ID</i>
Belgium		7,670 <i>ID</i>	
Bulgaria			
Cyprus			
Czech Republic	21 <i>MH</i> 143 <i>ID</i>	11,605 <i>MH</i> 15,100 <i>ID</i>	
Estonia			
Finland		4,854 <i>ID</i>	0.97 <i>ID</i>
France		73,700 <i>ID PD</i> 64,835 <i>MH</i>	
Germany		55,000 <i>MH</i>	0.4-0.8 <i>MH</i>
Greece	13 <i>ID</i>	34,432 <i>ID</i>	
Hungary	160 <i>All</i>	23,700 <i>All</i>	
Iceland	1 <i>ID</i>	227 <i>ID</i>	0.87 <i>ID</i>
Ireland		4,786 <i>ID</i>	1.36 <i>ID</i>
Italy	1,662 <i>All</i> 266 <i>ID</i> 423 <i>PD</i> 618 <i>Mixed</i> 1,307 <i>MH</i>		
Latvia			
Lithuania		5,143 <i>ID</i>	1.38 <i>ID</i>
Luxembourg	1 <i>MH</i> 38 <i>ID</i>	360 <i>MH</i> 632 <i>ID</i>	
Malta			
Netherlands	140 <i>ID</i>	34,000 <i>ID</i>	2.09 <i>ID</i>
Poland	160 <i>ID</i>	25,000 <i>MH</i> 23,465 <i>ID</i>	0.61 <i>ID</i>
Portugal			
Romania	150 <i>All</i>	52,500 <i>All</i> 13,374 <i>MH</i>	
Slovakia	5 <i>MH</i>	4,834 <i>MH</i>	
Slovenia	2 <i>MH</i> 5 <i>ID</i>	800 <i>MH</i> 808 <i>ID</i>	0.8 <i>MH</i>
Spain		11,535 <i>All</i>	
UK	399	20,654	0.35

<sup>17</sup> Hatton, Emerson and Kiernan, 1995; World Health Organisation, 2001.

<sup>18</sup> Sources: European Intellectual Disability Research Network, 2003; Hatton, Emerson and Kiernan, 1995; Inclusion Europe, 2003a, b; Inclusion Europe and the Association for Help to the Mentally Handicapped in the Czech Republic, 2002; Inclusion Europe and the Estonian Mentally Disabled People Support Organization, 2002; Inclusion Europe and the Hungarian Association for Persons with Intellectual Disability, 2002; Inclusion Europe and the National League of Associations for Persons with Mental Handicap, 2002; Inclusion Europe and the Polish Association for Persons with Mental Handicap, 2002; Inclusion Europe and the Slovenian Association for Persons with Intellectual Disability, 2002; World Health Organisation, 2001.

This means that, for many countries, it is difficult to be certain that the information about the institutions recorded in this project is representative of all institutions in that country. This difficulty confirms the validity of the European Commission's decision to sponsor this project but indicates that it is going to take more time to build up a comprehensive picture of institutional care in Europe. Governments cannot plan the modernisation of social care services and cannot compare themselves with partners in Europe without good comparative information.

Table 3 presents, for each country, the age groups served by institutions. Not all institutions completed all parts of the template, so that, for example, data were only available for 55 of the 399 UK institutions.

Table 4 shows the number of institutions reporting that they serve people with different types of disability.

In most countries over 80% of institutions served both genders, with some countries having a small number of single-sex institutions. The picture was slightly different in Poland, with 21% of institutions for men only and 17% for women only.

Most institutions (over 75%) in each country were accommodation facilities. The next most common type of institution was school or residential school, then residential treatment facility. In the United Kingdom, there was more variety in type of facility and in Finland 45% of institutions were described as treatment facilities.

**Table 3: Age groups served by institutions in each country**

	Age group of residents served			Total
	adults only	children only	both children and adults	
Austria	4	1		5
Belgium	12	5	5	22
Cyprus			2	2
Czech Republic	21		20	41
Estonia	2			2
Finland	79		6	85
France	11	5	2	18
Germany	4	1	2	7
Greece	1		2	3
Hungary	73	11	24	108
Iceland	1			1
Ireland	8		2	10
Italy	13	10	9	32
Lithuania	1	3		4
Luxembourg	2			2
Macedonia		3	2	5
Malta	1			1
Netherlands	1		13	14
Poland	276	27	42	345
Portugal	2		2	4
Romania	133	9	6	148
Slovenia	3		6	9
Spain	5		1	6
UK	42	10	3	55
<b>Total</b>	<b>695</b>	<b>85</b>	<b>149</b>	<b>929</b>

**Table 4: Number of institutions in each country reporting each type of disability**

	Disability						Total
	Intellectual disability	Physical disability	Mental health	Mental health and ID	ID and PD	ID, PD and MH	
Austria	1				3	1	5
Belgium	6	2	6	4	2	2	22
Cyprus	2						2
Czech Republic	25	1	1	5	5	4	41
Estonia			1	1			2
Finland	25	16	44				85
France	6	3		3	1		13
Germany	53			1	1		55
Greece	1				2		3
Hungary	63		6	14	20	4	107
Iceland	1						1
Ireland	7	1			1	1	10
Italy	9	5		1	11	1	27
Lithuania	3	1					4
Luxembourg	1	1					2
Macedonia	3	2					5
Malta			1				1
Netherlands	12	1			1		14
Poland	118	112	100	20	35	11	396
Portugal		1			2	1	4
Romania	1	41	79	7	3	16	147
Slovenia	6	1	1	1			9
Spain	15						15
UK	22	11	3	1	13	4	54
<b>Total</b>	<b>380</b>	<b>199</b>	<b>242</b>	<b>58</b>	<b>100</b>	<b>45</b>	<b>1,024</b>

Ten percent of all institutions (243, serving over 30,250 people in 17 countries) responded to the request to supply more detailed information. This is likely to have been due to the short time available between receiving the first notification and the end of the project. This information represents a promising area for future work. Table 5 shows, for those institutions that supplied the more detailed information, the mean number of residents per institution, how many people shared a bedroom and the length of stay. There is a considerable range in the age of institutions recorded. Six countries have institutions over 100 years old, five have institutions opened in the last five years. In most countries, people share a bedroom.

Although in every country for which there are data there are many residents who have been in the institution for many years, there are also people who have been admitted recently. What these data indicate is that institutional care, although the preferred model of the past, is still being sustained through new building and new admissions.

Institutions were also asked whether they served people mainly from their own locality or whether they provided accommodation and support for people from further away (Table 6). These data show that, in many institutions, the communities from where residents originated, as well as their families and friends, are a long way away.



**Table 5: Resident numbers, sharing and length of stay**

Country	Number of institutions	Mean age of institution in years (min-max)	Mean number of residents per institution	Mean number of people sharing bedroom (min-max)	Mean % of residents <2 years in institution	Mean % of residents between 2-11 years in institution	Mean % of residents >11 years in institution
Austria	2	95 (32-158)	110	2.5 (1-5)	15.8	14.0	70.2
Belgium	12	31.2 (7-54)	78	2.3 (1-12)	32.3	35.6	32.2
Czech Republic	23	35.8 (3-85)	108	3.4 (1-39)	22.7	23.9	54.6
Estonia	1	9	34	3 (2-4)			
Finland	4	13	235	1.75 (1-3)	55.0	31.5	13.5
France	10	15.22 (2-28)	38	1.1 (1-3)	16.8	52.7	30.5
Germany	6	94.8 (24-152)	158	1.25 (1-3)	36.2	22.7	41.1
Greece	1	25	55	2			
Hungary	36	44 (18-144)	145	4.9 (1-11)	22.4	36.5	40.8
Ireland	5	37 (33-41)	121	3.5 (1-8)	51.4	2.4	46.2
Luxembourg	2	29 (24-34)	101	1 (1-2)	54.2	42.4	3.5
Netherlands	5	36.3 (12-74)	779	1 (1-3)	27.5	19.1	53.4
Poland	54	36.9 (1-104)	126	4.5 (1-19)	31.3	35.7	37.9
Portugal	2	26.5 (17-36)	81	2 (1-4)	48.4	23.9	27.8
Romania	33	36.5 (1-106)	122	5.7 (1-21)	56.4	32.7	10.9
Slovenia	3	80	245	2.76 (1-2)			
Spain	3	20	50	1.33 (1-3)			
UK	41	39.8 (4-129)	59	1.1 (1-4)	38.5	33.6	34.5

Institutions were provided with a list of 11 types of professional support (e.g. medical doctor, therapist, social worker) and asked whether residents obtained these services within the institution or in the community. Proponents of such models of care often argue that an

advantage of grouping disabled people in institutions is that specialist services can be provided on site. Critics argue that onsite institution services are often inferior to those available to the general population and that using services in the community aids social integration.

**Table 6: Institution catchment area policy**

	Non-local catchment	Local catchment	Total
Austria	0	2	2
Belgium	9	3	12
Czech Republic	15	7	22
Estonia	1	0	1
Finland	2	0	2
France	2	8	10
Germany	1	4	5
Hungary	32	2	34
Ireland	1	2	3
Luxembourg	1	1	2
Netherlands	0	5	5
Poland	28	21	49
Portugal	1	1	2
Romania	1	27	28
Slovenia	2	0	2
Spain	0	3	3
UK	28	10	38
<b>Total</b>	<b>124</b>	<b>96</b>	<b>220</b>



Table 7 shows the average number of specialist services available onsite or offsite and the average number of services available to institutions in each country. Within each country there was wide variation, with some

institutions providing most services onsite and others supporting residents to use services in the community. Apart from the UK and Germany, most countries generally provide the majority of services inside the institutions.

**Table 7: Specialist services**

Country	Mean number specialists onsite	Mean number specialists offsite	Mean number specialists both onsite and offsite	Mean number of specialists accessed (max=11)
Austria	0.00	1.00	0.00	1.00
Belgium	3.42	1.42	0.42	5.25
Czech Republic	4.48	1.43	0.57	6.48
Estonia	1.00	2.00	0.00	3.00
Finland	4.75	2.75	1.25	8.75
France	1.30	2.30	0.00	3.60
Germany	0.50	7.33	0.83	8.67
Hungary	3.42	0.97	0.19	4.58
Ireland	4.00	1.00	0.00	5.00
Luxembourg	2.50	0.00	0.00	2.50
Netherlands	5.40	0.60	0.20	6.20
Poland	4.24	1.78	0.38	6.40
Portugal	7.00	1.00	0.00	8.00
Romania	3.12	0.33	0.12	3.58
Slovenia	3.33	0.00	0.00	3.33
Spain	4.00	0.33	0.67	5.00
UK	2.29	4.95	0.56	7.80
<b>Total</b>	<b>3.38</b>	<b>2.02</b>	<b>0.36</b>	<b>5.75</b>

## The revenue cost of residential institutions compared with community services

Substantial research has been done in several countries comparing of the revenue cost of residential institutions with those of community services. However, the results are not uniform: Research from North America suggests that community-based service systems are not more expensive than the institutions they replace; research from the United Kingdom shows that they are. What explains these different results?

First, the characteristics and needs of service users are important. If institutions cater for many people with relatively mild disabilities (or even people who are not disabled at all), then insofar as these people can live successfully in the community with less support they get in the institution, the cost of replacing institutional care for them will be lower. For people with higher support needs however, this is not likely to be the case.

Furthermore, the relative quality of institutional and community care is important. Institutional costs have been rising over time in both North America and the UK. This partly reflects the increasing disability levels of the resident population and partly reflects the need to improve standards of care. The resident population has tended, over time, to include fewer people with low support needs. The number of staff required is increased because of greater proportion of residents with high support needs. In addition, when many people with low support needs were kept in institutions they often helped care for residents with high support needs, by assisting staff. The fact that these people are no longer available to share the caring task means that more, and better-trained staff must be made available.

Thus, the comparison for decision-makers should not be between institutional costs now and the costs of community services in the future, but between what it would cost to provide institutions that have come as close as possible to achieving the same results as community-based services. In both Scandinavia and the USA, institutions became at least as expensive as the alternatives in the community. This was primarily because they were obliged to spend more in order to achieve minimally acceptable levels of care. Decision-makers then faced a choice between spending roughly the same amount of money on institutions or replacing them with services in the community which achieved better results. In the UK, institutional costs also rose over time in response to criticism of the quality of institutional care. However these costs still remained lower than the cost of providing better services in the community.

The implications of this analysis are as follows:

- For those people with low support needs, the cost of the services they need, provided in the community on an individualised basis, making the most of their abilities to look after themselves and perhaps contribute to the economy, is likely to be lower than the cost of institutional care.
- For people with higher support needs, the cost of community services is likely to be higher than the cost of poor-quality care in institutions, but it is likely to be the same as the cost of institutional care which has been forced to raise its standards.
- In countries with large institutions serving many people with low support needs, the savings made in moving to community-based provision will help offset the costs of doing so for people with high support needs.
- For most practical purposes, the cost of staff is the critical factor. Lower costs mean less staff support available to each disabled person. For people with high support needs, less staff support is likely to mean that they have fewer opportunities and a worse quality of life. If sufficient staff are provided, then community-based services are no more expensive than institutions and can achieve better results for the people they serve.

## 2 In-depth study of institutions in four countries

In some European countries there is a relatively large body of research evaluating different models of accommodation and support for disabled people. There is also a great deal of information from research in North America and Australasia. The in-depth study aimed to describe institutional care in countries where there has been relatively little research and evaluation of services for disabled people. Given the resources available, fieldwork was carried out in one EU15 member state (France), two new member states (Hungary and Poland) and one applicant country (Romania).

In each country, local researchers were recruited. Those in Hungary, Poland and Romania were managed by the Centre for Policy Studies at the Central European University. The researcher in France was managed by the Association for Research and Training on Integration in Europe (ARFIE). Researchers were trained in the use of the instruments and questionnaires developed for the study and maintained frequent email contact to coordinate their work and resolve queries.

The local researchers identified institutions believed to be typical of the range and type of provision in that country according to agreed guidelines. In the absence of detailed national data on institution numbers and characteristics it was, of course, not possible to sample in a scientifically rigorous way.

Following the initial identification process institutions were contacted and visited. The institution manager was interviewed and two to five living units (wards or buildings) were selected for more detailed study. It was planned to ensure the inclusion of services for people with intellectual disabilities, mental health problems or physical disabilities and to include living units for children as well as adults. Researchers aimed to include 20 living units in each country and in each case this meant visiting six or seven institutions.

First, the living unit was visited, the manager interviewed and time was spent by the researcher observing the environment, the residents and staff and completing various rating scales and observations according to a detailed protocol. Details of the methodology and measures used are available from the project partners.

Researchers also carried out a literature review of studies of de-institutionalisation and quality of care relating to Eastern European and Francophone countries. The Tizard Centre reviewed the English literature. This information was then used to provide context and background for the interpretation of the data from the four countries studied.

Unfortunately, the researcher managed by ARFIE was unable to complete all the measures for French institutions and the literature review and these pieces of work have therefore, not been included in this report.

### Description of institutions

Table 8 presents summary information about the institutions from which the sample described below was taken. Most institutions were for adults only, one institution in Romania (No 5) and one in France (No 1) was for children only whilst one institution in Hungary (No 5) and another in Poland (No 5) served both children and adults. For the most part, the gender of residents was mixed - only two institutions served male-only residents (one in Hungary (No 4) and one in Poland (No 5)). In Hungary and Poland, all institutions were designed to serve people with different disabilities, but in Romania only one served a mixed population (No 6), three (Nos 1, 2 and 4) served those with physical disabilities. Meanwhile one served people with intellectual disabilities (No 5) and one (No 3) people with mental health problems. In France, three (Nos 2, 5 and 7) were mixed, two (Nos 1 and 4) served those with physical disabilities and two (Nos 3 and 6) served those with intellectual disabilities.

**Table 8: Institutions included in in-depth study**

Institution	Maximum capacity	Number of residents	Number of living units	Level of government	Resident/staff ratio	Residents local?	Year open	Typical length of stay (years)
Hungary1	400	403	7	Regional	3.45	Yes	1950	Life
Hungary2	300	268	6	Regional	4.55	No	1954	Life
Hungary3	120	121	2	Regional	2.78	Yes	1969	Life
Hungary4	180	184	5	Regional	2.63	Yes	1979	Life
Hungary5	270	274	5	Regional	2.56	Yes	1956	Life
Hungary6	128	128	4	Regional	3.70	No	1965	Life
Poland1	103	103	8	Local	6.25	Yes	1994	>10
Poland2	110	110	6	Regional	5.00	Yes	1972	30-40
Poland3	110	112	4	Local	5.56	No	1958	20
Poland4	102	102	2	Local	2.70	Yes	1997	5
Poland5	100	100	10	Regional	3.13	No	1956	30
Poland6	131	130	5	Regional	1.92	No	1952	20
Romania1	113	112	2	Local	1.64	Yes	1959	Life
Romania2	80	90	2	Local	1.30	Yes	1964	15
Romania3	140	173	3	Local	2.08	No	1978	10
Romania4	101	96	2	Local	2.27	No	1979	15
Romania5	70	67	3	Regional	1.75	No	1979	12
Romania6	250	246	6	Local	4.55	No	1968	15-20
France1	120	120	3	National	3.57	Yes	1969	6
France2	45	63	3	Local	3.33	Yes	1976	Life
France3	50	52	4	Local	1.79	Yes	1975	30
France4	520	500	15	National	1.89	No	1855	4
France5	57	57	7	National	1.59	Yes	1984	10
France6	151	151	3	Local	<sup>19</sup>	No	1986	Life
France7	105	105	10	Mixed	1.47	Yes	1977	Life

Table 9 summarises information about the space available in the living units studied, and the extent to which people have to share bedrooms and living rooms.

In Romanian, Hungarian and Polish institutions, arrangements can be made for people to cohabit as a couple if they want to but this is generally only allowed if they are married. In French institutions, no institutions reported any such arrangements in place or it was

**Table 9: Size and sharing of living unit space**

Country	Number of people sharing a bedroom (min-max)	Number of people sharing a living room	Mean sleeping area per person (m <sup>2</sup> )	Mean living area per person (m <sup>2</sup> )
Hungary	2-7	27-57	6.08	1.00
Poland	1-3	3-47	7.02	2.48
Romania	3-10	45-61	4.83	0.62
France	1-3	3-15	12.14	8.71

<sup>19</sup> No staff data available.



**Table 10: Number and size of living units participating in in-depth study**

Country	Number of Living units	Number of institutions	Number of residents	Mean no of residents per living unit (min-max)	
Hungary	20	6	988	49.40	(19-78)
Poland	20	6	405	20.25	(7-61)
Romania	16	6	761	47.56	(10-90)
France	22	7	297	14.14	(8-24)

reported that the people living there were considered 'too disabled' to want to cohabit.

Institution managers were interviewed about the governance arrangements, visiting arrangements and individualised planning. Given recent concern about the use of 'cage beds' in institutions<sup>20</sup> managers were also asked about this and other methods of restraint and treatment.

In all institutions, managers said that people had the right to complain, with 13 units having a written complaints procedure. In all countries, with the exception of Poland, there was a management committee, but in only four of the Romanian institutions and in one of the French institutions were there resident representatives on these committees. A few other institutions, in particular those in France, had family representatives on the management committee. In most of the institutions people could visit on any day, however, often at set times only. Only in one French institution were people only allowed to visit on certain days. In Hungarian, Polish and Romanian institutions, visitors could move freely within the building, but in French institutions, visitors were restricted to the living unit only and in some cases to certain areas within that living unit.

All institutions, with the exception of one in Romania reported drug (chemical) treatments in use for behaviour management, but no institutions reported the use of electro-convulsive therapy. Four institutions in Poland and three in France reported using cage beds. Five institutions (none in Romania) used exclusion rooms. Restraint was in use in some form in most countries apart from France where it was reported that residents were excluded from the institution if their behaviour presented a problem.

At least some residents in every institution studied were reported to have a person-centred or individual plan, which, for the most part, was reviewed at least once a year. Two institutions in Romania, however did not review plans at all. In Hungary and France, most people followed timetabled activities. Two institutions (one in Poland and another in Romania) offered people no timetabled activities. All but one of the Hungarian institutions reported that at least some of the residents were involved in choosing their daily activities.

### **Living units studied**

Table 10 shows the number of living units visited in each country, together with the total number of residents in all the institutions on which data were gathered. The last column shows the average number of residents per living unit (and the maximum and minimum) for each country. Living units in France and Poland were smaller than those in Hungary or Romania, although still larger than many private households.

### **Resident needs and characteristics**

#### **Type of disability served**

Despite the designation of some institutions as serving people with particular disabilities, living unit managers in the majority of the living units in all four countries said that residents included people with more than one type of disability. In 63 (out of a total of 78) living units, more than 90% of residents had more than one type of disability. In seven living units (five of which were in France), every resident was rated as having multiple disabilities. Table 11 shows the number of residents in each country with different disabilities. It should be noted, that in Romania, the distinction between mental

<sup>20</sup> e.g. Mental Disability Advocacy Center, 2003

**Table 11: Percentage of residents with different disabilities**

Country	ID	PD	MH	Multiple
Hungary (n=988)	46%	0%	13%	41%
Poland (n=405)	19%	4%	21%	57%
Romania (n=759)	15%	24%	41%	20%
France (n=297)	21%	9%	3%	67%

**Table 12: Mean percentage of residents in each age group in each country**

Age Range	Mean percentages of residents in each age group			
	Hungary	Poland	Romania	France
<16	4	1	4	2
16-19	4	1	5	10
20-29	16	11	8	32
30-39	21	18	9	21
40-49	21	18	9	21
50-59	15	20	12	16
60-69	11	16	14	2
70-79	7	12	21	0
80-89	2	4	14	0
90-100	3	1	3	0

illness and intellectual disability was not always recognised so that it would not be safe to assume that the Romanian sample included fewer people with intellectual disability.

#### Age

The mean ages of residents were: Hungary, 43, Poland, 51, Romania, 57 and France 35. In the living units sampled in Hungary and Poland, the majority of the residents were between the ages of 20 and 80. In Romania the majority of the residents were in the age range 50 to 90 and in France, they were between 16 and 60, with no residents over the age of 70 in the sample (Table 12).

#### Length of stay

Table 13 shows the length of stay of residents in the current living unit. The differences between countries are statistically significant. Living unit managers in Hungary reported the longest length of stay of residents in their

current living unit and Romania the shortest. This may reflect greater movement of residents from one living unit to another or from institution to institution as governments attempt to modernise services.

#### Support Needs

Living unit managers were asked to assess whether each of their residents had high, medium or low support needs. The striking finding here (Table 14) is France, where a much higher proportion of residents were said to have low support needs than in the other countries. Although this may of course reflect differences of interpretation or differences of sampling, Bon (2004) reports that about 40% of French residential services provide for people who are able to work and that about 77% of the residential settings have over 50 places. The finding reported here may therefore reflect actual practice in France.

**Table 13: Mean length of stay and range in years in current living unit**

	Hungary	Poland	Romania	France
Mean length of stay (range)	14 (<1-53)	10 (1-40)	8 (< 1-36)	11 (1-28)

**Table 14: Percentage of residents in each country who were rated as having high, medium or low support needs**

Support Needs	Hungary	Poland	Romania	France
High	46%	33%	37%	19%
Medium	31%	49%	35%	32%
Low	23%	18%	28%	49%

Hungary and Romania show similar patterns of residents' needs, housing more people with high support needs, whereas in Poland the largest group of residents were people with medium support needs.

#### Dangerous behaviour

On average, 14% of residents in institution in Hungary, 21% in Poland, 13% in Romania and 22% in France were rated by the living unit managers as 'dangerous'.

#### **Contact with family and friends**

One of the major disadvantages of large residential institutions is the creation of barriers to sustained contact between the resident and their family and friends. Even if family and friends are not actively discouraged from maintaining contact, the difficulty and expense of regular visits to institutions a long way away is difficult to overcome.

"The connection with family is very weak. Very few children receive visits, or are taken out of the institution". (Romania)

"Despite the efforts of management, contact with the outside world is rare; visits of relatives are not frequent and due to lack of money, no outgoing visits (tourism, culture) are undertaken." (Poland)

"Theoretically, visits should take place only Mondays, Wednesdays, Fridays, Saturdays, and Sundays 3 - 6 pm. Actually, visitors are allowed in any day, but they are expected not to arrive later than 7 pm, when most patients go to sleep. Since many patients cannot move, they have to be visited in the bedroom". (Romania)

Table 15 shows the mean percentage of residents in each country receiving various kinds of contact from family and friends. In general, a minority of residents receive contact from family or friends at least once a month. In Hungary, Poland and Romania, the general picture is of many people not receiving any contact at the institution and the majority never going out to visit family or friends at their home.

The pattern reported is somewhat different in France. There, most people were reported to have contact with their family, less than once a month. Three-quarters of residents were never visited by friends and two-thirds never went out to visit friends.

#### **Physical environment**

Living units were sometimes part of old buildings and were sometimes relatively new. Generally, the living units required many people to share living areas, bedrooms, bathrooms and toilets, though French institutions required fewer people to share rooms and facilities.

"The rooms are huge, with too many beds. Some rooms open from each other, and there is no room for anything, except to lay on the bed... There are bars on the windows in the rooms for security reasons. Hospital beds are in the bedroom, and there is no room for anything but beds. Only the most able people have ordinary beds and their own cupboards, but these rooms are still not like home. The toilets have no partition, the bathrooms are in very bad condition." (Hungary)

**Table 15: Contact from family and friends**

	Hungary	Poland	Romania	France
<i>Visit from family</i>				
Weekly	1%	3%	7%	7%
Monthly	18%	11%	20%	26%
Less than monthly	47%	37%	24%	55%
Never	34%	50%	49%	12%
<i>Other family contact</i>				
Weekly	6%	7%	9%	2%
Monthly	15%	19%	26%	12%
Less than monthly	35%	22%	20%	74%
Never	44%	53%	45%	13%
<i>Go home</i>				
Weekly	2%	0%	0%	5%
Monthly	9%	4%	4%	23%
Less than monthly	25%	23%	14%	60%
Never	64%	72%	83%	12%
<i>Friends visit</i>				
Weekly	6%	4%	2%	1%
Monthly	3%	12%	11%	0%
Less than monthly	16%	13%	9%	24%
Never	75%	70%	79%	75%
<i>Go out to visit friends</i>				
Weekly	1%	6%	0%	1%
Monthly	1%	15%	1%	5%
Less than monthly	8%	9%	4%	27%
Never	90%	70%	95%	67%

“The building is old and in bad shape. There have been refurbishments (new furniture, lots of televisions), but there is not enough funding to improve the building itself.” (Romania)

“Bathrooms and toilets are few, so despite staff’s effort to keep them clean they smell. Residents are not allowed to smoke in rooms, so they smoke in bathrooms. The general living-dining area and small areas at the ends of corridors do not meet residents’ needs for living space. Among the cupboards, there are televisions in the corridors for residents’ use, with the row of chairs in front of the area.” (Poland)

“This place is in very bad condition, with leaky roofs and damp walls. The corridor is covered with hospital style tiles, rooms are small, the beds are like those in hospital, and there were a few cage beds (what they called a ‘half-cage bed’, because there is no roof on it). Residents eat in their bedrooms. Some of them are fed by the staff either in their bed or they are put in a wheelchair. The odour was stuffy.” (Hungary)

“Many patients cannot get out of bed; therefore the living areas are not that crowded.” (Romania)

Table 16 shows the characteristics and quality of the physical environment in each country.

Researchers rated the cleanliness and neatness of living units they visited. In Hungary, the condition of dining areas was generally rated 2 and above, on a scale of 0 (worst) to 4 (best). However, in 3 out of the 6 units which had a dining area, the condition of furniture was rated 1. Two units were reported to have quite bad smelling odours. Living rooms were in poorer condition, with 15% being untidy, 20% being dirty, 20% containing furniture in poor condition, and 15% bad smelling. A very similar picture was found for bathrooms. Bedrooms/sleeping areas were generally cleaner and tidier but in 50% of units the furniture was reported to be in poor condition.

The situation observed in Polish, Romanian and French institutions was slightly better in terms of conditions, with very few scores being below 2 on these items.

In general, living units had curtains, and a reasonable selection of furniture, even if these were of low quality and not in good condition. However, 44% of units in Romania, 50% of units in Poland and 65% of units in Hungary were rated as not having suitable floor coverings in any sleeping areas/bedrooms. In France, this was the case in only 18% of units.

In French institutions, almost all living units had personal decoration in at least some of the bedrooms, usually photographs. In Poland, in 5% of the units, the bedrooms had no personal decoration; in Hungary this was 25% and in Romania it was 44%.

The researchers were asked to rate how much like a 'normal' home they perceived rooms within living units to be. Researchers compared living units with the cultural norms for the country (the researchers were all familiar with cultural norms in the countries

**Table 16: Characteristics and physical quality of living units in each country**

	Hungary	Poland	Romania	France
Age of buildings: mean years (min-max)	53 (1-219)	37 (3-80)	49 (1-100)	39 (5-134)
<i>Eating Areas</i>				
Central dining room (%)	65%	60%	31%	57%
<i>Living Areas</i>				
Living areas per living unit (mean)	1	1	1	2
Number of people using living area (mean)	41	24	49	13
<i>Bathrooms</i>				
Bathrooms per living unit (mean)	3.15	2.60	3.44	3.41
Number of residents per bathroom	14	8	10	4
Living units with no partitions in bathrooms (%)	40	10	71	18
<i>Toilets</i>				
Toilets per living unit (mean)	6.4	3.95	4.88	6.68
Number of residents per toilet	8	5	8	2
Living units without partitions and doors in toilets (%)	40%	35%	19%	35%
No toilet paper in toilets (%)	70%	60%	88%	0% <sup>21</sup>
<i>Sleeping Areas</i>				
Sleeping areas per living unit (mean)	11	8	9	9
Number of beds per sleeping area (min-max)	1-14	1-5	1-18	1-8

<sup>21</sup> Data only provided for 14 of 22 living units.

**Table 17: Resident/staff ratios**

	Residents per care staff post			Residents per care staff observed		
	Mean	Min	Max	Mean	Min	Max
Hungary	3.2	1.5	4.8	44.6	10.0	– <sup>22</sup>
Poland	4.3	1.9	7.0	6.8	1.5	19.0
Romania	2.5	1.4	5.3	4.6	3.1	18.0
France <sup>23</sup>	5.9	2.2	14.0	4.0	1.3	-

researched). The ratings were entered on a five-point scale. French institutions were rated as most homelike (mean 2.85, range 0.5–4.0), Polish institutions came next (mean 1.45, range 0–2.8) and Romanian and Hungarian living units were both rated as being least homelike (Hungary mean 0.49, range 0–3.0; Romania mean 0.55, range 0–0.8).

## Staffing

### Staff ratio

In Hungary, Poland and Romania it was usual for all staff to work full-time, whilst in France many living units employed a mix of full-time and part-time staff. Average full-time working weeks consisted of 40 hours in Hungary, Poland and Romania and 35 hours in France. Table 17 shows staff ratios – the number of residents to each member of staff.

The French data presented here relates only to 14 of the 22 living units and includes the lowest staff ratios found. This is consistent with the much higher proportion of people with low support needs in the French institutions (see Table 14). The much higher staff ratios reported by living unit managers in Romania than those found in Hungary or Poland is surprising, especially given previous reports about staffing in Romanian institutions, and this point requires further investigation.

The ratios of residents to staff in post are overall ratios and, of course, the number of people cared for by each member of staff will be much higher than this when one takes account of patterns of shift work. In one

institution in Poland it was noted that most staff worked from early morning until the afternoon, after which there was only one member of staff on duty. The observed staff ratios give a ‘snapshot’ of the staff ratio at the time of the researchers’ visits to institutions. These ratios were calculated by recording the number of residents in the living units at the time of the researchers’ visit and the number of staff who were available to the residents at that time.

In Hungary, 8 of the 18 living units where observational data on staff activity was recorded had no staff available to the residents (in one living unit, the only member of staff was talking to the researcher, in another all staff were in a meeting, and in others, staff were on breaks or elsewhere). This situation was also encountered in one living unit in France. Where staff were available, they were engaged in different ways – sometimes with residents (for example, feeding them, supporting them to take part in activities, personal care etc, or just being in a room with the residents), however, sometimes they were engaged only with other staff members, for example, in an office talking.

### Training

Living unit managers were asked about care staff qualifications (these data were not collected in France). Table 18 shows the mean percentage of staff with different levels of training in living units in each country. The majority of staff in each country were said to have had some training, with the lowest proportion of trained staff in Romania.

<sup>22</sup> No staff were observed to be available to residents

<sup>23</sup> Data only provided for 14/22 living units



**Table 18: Proportion of staff with training**

	University degree	College qualification	School certificate	In-service	None
Hungary	1%	3%	37%	50%	9%
Poland	17%	47%	26%	3%	7%
Romania	3%	17%	45%	12%	22%

### Specialist input

Table 19 below illustrates different types of specialist treatment provided in living units in each country. Where data was not provided, it has been assumed that this service was not available. In a few cases, the number of units providing a service onsite and offsite exceeds the total number of units because the service was provided onsite for some people and offsite for others.

### Daily lives of residents

#### Quality of Care

This study used a standard measure (the Revised Resident Management Practices Scale), which has been utilised in other studies<sup>24</sup>, to investigate four features of institutional care:

- How fixed the daily routine is – for example, do people have to eat or go to bed at the same time? (rigidity of routine)
- Whether people are treated as a group or as individuals (block treatment)
- Whether people are allowed to have personal possessions e.g pictures, clothes and to express their individuality (depersonalisation)
- Whether staff keep themselves very separate from the people they serve (social distance)

Table 20 shows the average scores gained by living units in each of the four countries studied, expressed as a percentage of the total score possible. The higher the score, the more institutional the pattern of care – that is, care is provided with greater emphasis on the

**Table 19: Specialist support in each living unit**

	Hungary (n=20)		Poland (n=20)		Romania (n=16)		France (n=22)	
	Onsite	Offsite	Onsite	Offsite	Onsite	Offsite	Onsite	Offsite
Medical treatment	19		15	6	16		16	6
Dental treatment	13	1		20	3	10	7	14
Social worker	16		20		6		4	10
Psychologist			5	5	16		18	2
Orthopedagogue	9		13		3		4	
Occupational Therapist	9		16		11		11	
Speech and Language therapist			1	3			7	5
Physiotherapist	5		9		16		18	3
Education			3	3	3		12	
Work	13	10	1	4			9	1
Information/advocacy			1	3		3	6	1

<sup>24</sup> King, Raynes and Tizard, 1971; McCormick, Balla and Zigler, 1975; Raynes, Pratt and Roses, 1979

needs of the institution than on the needs of the individuals living there.

These data show some variation in every country. Romanian services were rated as much more institutional than those in Poland, Hungary or France. Although the maximum score for French services is lower than the maximum in other countries, the difference between French and Polish services was not statistically significant.

Qualitative data recorded by the researchers (see boxes) explains what this meant in practice (these data were not provided for France).

### Rigidity of routine

“Residents can wake or go to bed whenever they want to, however, breakfast is at a set time in the morning, and medication is given in the evening, so in practice all residents wake up and go to bed at the same time.” (Hungary)

“The manager said that most of the residents go to bed at 20:00 hrs – but if someone did not want to go to bed at this time they would have to be silent so as not to disturb the other residents.” (Hungary)

“A normal day schedule consists of waking up, washing, dressing up (7.30 - 8.00), breakfast + medication, kindergarten programme, snack (10.00), lunch + medication (12.30 - 13.30), toilet, nap (13.30 - 16.00), kindergarten programme or TV (16.00 - 19.30), dinner + medication (19.30 - 20.00), toilet, going to bed (21.00)” (Romania).

### Block treatment

“There is a conveyor belt system while bathing the residents” (Poland)

“There is a so called ‘pot the baby’ time. I saw 10 adult residents were sitting in line on an old style pot in the bathroom.” (Hungary)

“Clothes are kept all together for each dormitory”. (Romania)

“Residents have to leave their rooms anyway at cleaning time. After breakfast and lunch they go to the so-called ‘collector’ where they have to wait until the cleaners finish their work.” (Hungary)

### Depersonalisation

In a Romanian institution for children aged 3-20 “none of the residents have personal possessions”.

“The term ‘kindergarten’ was used in relation to all residents, even those in their late teens. The manager said that the residents were both physically and intellectually ‘younger than their biological age, for example none of them can write’ – therefore they were treated as young children” (Romania)

“Residents who stay in bed all day do not have any day clothes, only pyjamas” (Romania)

“Most of the residents wear a sweat suit or pyjamas, but some of them were half or

**Table 20: Institutional quality of care**

Country	Mean	Std. Deviation	Minimum	Maximum
Hungary	29.5	11.3	14.3	51.8
Poland	20.8	12.1	3.6	48.2
Romania	40.7	16.3	21.4	71.4
France	17.3	6.1	7.1	25.0

completely naked. ... Residents were eating from plastic plates; they had tin cutlery and plastic glasses. All of them have diapers, so there is no toilet at night and none of them use the shower, two third of the residents stay in bed all day long and they are fed in their bed.” (Hungary)

“There is also no privacy in the rooms; staff visit each room every 15 minutes and the door must not be locked. There are no common living areas for residents at floors, but central one in each building.” (Poland)

“The hair style is also typical, just a few of them take care of the style, the others have very similar, short hair.” (Hungary)

### Social distance

“The three nurses were in their room” (Hungary)

“Regulations prohibit the involvement in the kitchen of people apart from staff” (Romania)

However, practice varied and a consistent theme in researchers’ comments was that staff were sometimes trying to overcome the worst practices of institutional care, although they faced many obstacles in terms of resources and ideology.

“The concept is changing slowly, but changes take a long time. Theoretically they express a more liberal and modernized methodology with the residents, but in practice they do not use it in many cases”. (Hungary)

“The Board is trying to sneak within the rules to introduce new ideas, forms of activities for residents, which do not always fit the regulations.” (Poland)

“Most of the residents need little support, but because of the place, staff are not able to help them integrate into society. The management team have a so-called modernization program which tries to educate the residents for an independent life. They have a small group home in the village and they want to build new ones... According to the director, these people would not be in institutions in western countries, some of them would not even be considered disabled.” (Hungary)

I saw here the most disabled people. Despite that, I experienced here the most innovative program... They have three small group homes, which I also visited. They are very nice homes, richly furnished. The nurses are behaving like at home, dressing like at home...but despite this, it is still an institution. (Hungary)

### Choice-making and autonomy

Living Unit Managers were asked whether their residents were encouraged to make choices and have control over things such as:

- choosing food, for example what to eat or what to leave at any meal
- their environment, for example, having pictures in their rooms

**Table 21: Community involvement**

	Hungary	Poland	Romania	France
Mean % score per living unit (range)	11% (0-33%)	14% (0-62%)	2% (0-8%)	21% (0-47%)

**Table 22: Participation in daily living**

	Hungary	Poland	Romania	France
<i>Support needs</i>				
Low	56%	56%	30%	48%
Medium	37%	37%	19%	19%
High	11%	11%	7%	30%

- clothes, for example what to buy and what to wear on a daily basis
- having an outer door key
- going out to meet friends
- choosing how to have their hair styled
- using public transport on their own

Generally the same pattern was found as for daily living activities – more choice is afforded to those residents with the lowest support needs. There were no statistically significant differences between countries. Although some living unit managers reported offering quite a lot of choice to their residents, the researchers noted that such choices were in fact limited (see box).

“There is practically no daily programme, so people have a lot of choice in deciding what to do; they mostly watch television, some read, or play social games.” (Romania)

“Patients can make choices on what to buy with their money (but they do not have much of it). Otherwise there is no choice of meals, cosmetics etc. which are offered free by the institution. People could use personal items to decorate the rooms. They could ask the support staff to vary the room temperature (patients are not allowed to interfere with the heating system); they could open the window if it is too hot, but everyone in the bedroom has to agree. If they want to be alone, they could go into the hallway. It is theoretically possible for people to get organized if they require an outing or to go out and visits their friends - it just does not happen.” (Romania)

“The gates were locked at 10 pm – residents could be out later, but had to make arrangements prior to leaving the institution.” (Hungary)

“The main entrance to the buildings is always locked but can be opened on request of the residents. Guest visits are controlled. Night visits are not allowed” (Poland)

#### Community involvement

To assess the extent to which residents undertook social and community activities, living unit managers were asked how many people had, in the last month, undertaken activities such as:

- going to a cinema or theatre
- going shopping
- going to a place of worship
- and, in the last year, how many residents had been on holiday

Higher scores on this scale indicate better levels of community involvement. Table 21 gives mean percentage scores obtained in Hungary, Poland, Romania and France.

#### Participation in daily living

Living unit managers were asked about opportunities for residents to take part in everyday activities such as helping to prepare meals, washing clothes and helping in the garden. In so far as the purpose of services for disabled people is the provision of support with life-skills or rehabilitation, it is relevant to ask to what extent they support people to participate in activities of daily living.

Table 22 shows the score on this rating scale, expressed as a percentage of total possible

**Table 23: Resident engagement in activity in each country**

Country	Support needs	Percentage engaged in any activity (including watching television, smoking)		Percentage engaged in active leisure, household or work-based activities	
		Mean	Min-max	Mean	Min-max
Hungary	Low (n=10)	23.2	0-100	13.3	0- 79
	Medium (n=10)	19.9	0-79	8.3	0- 40
	High (n=11)	4.6	0-28	0.9	0-10
Poland	Low (n=20)	87.5	50-100	32.0	0-100
	Medium (n=20)	65.5	0-100	25.5	0-100
	High (n=15)	26.8	0-100	0.5	0-8
Romania	Low (n=15)	37.4	0-100	5.1	0-50
	Medium (n=15)	45.5	0-100	0.0	
	High (n=16)	15.7	0-100	0.0	

n=mean number of residents observed in each unit

score, for people with low, medium or high support needs in each country. The higher the score, the greater the opportunity for participation in activities of daily living. For Hungary, Poland and Romania, there is a clear relationship between the level of staff support needed by residents and the opportunities for participation, with the most independent people having most opportunities. In France, people with high support needs had more opportunities than did those with medium support needs.

However, in all countries studied, the level of opportunity for participation in daily activities was rather low. Even simple kitchen tasks were unavailable to most of the residents – there were living units that had kitchens but, for the most part, residents were not allowed to use them.

The extent to which residents were engaged in meaningful activity, and were appropriately supported by staff to do so, was also observed by researchers on their visits to living units. No observational data was received from France, therefore the results of this part of the study relate only to Hungary, Poland and Romania. Engagement in meaningful activity is a widely used measure of service quality and this addresses the question of whether, in spite of their disabilities, residents are being enabled to actually take part in activities of daily living.

Table 23 presents the proportion of people who were (a) engaged in any activity other than sitting, standing, pacing, walking about, lying or sleeping and (b) engaged in active leisure (e.g. sewing, embroidering), household activities or work-based activities, when observed on the living unit.

**Table 24: Staff activities on living units**

	Hungary (n=18)	Poland (n=18)	Romania (n=16)
No staff seen	5	0	0
Sitting with/supervising/checking/dealing with residents	4	5	11
Feeding/dressing residents or giving medication	0	6	2
Preparing food/drinks/cleaning unit	2	3	3
Engaging residents in educational/occupational activities	1	0	0
Talking to residents/assisting them	2	4	0
Sitting in nurses office/staff meeting	3	0	0

n=number of living units where observations made

Focusing first on the extent to which residents were enabled to take part in household, work or active leisure activities, these data reflect the patterns observed in other areas, i.e. that the more disabled the person, the less involvement they have. When passive leisure activities like smoking and watching television are included, this pattern is repeated in Hungary and Poland (in Romania more people with medium support needs than those with low support needs were engaged in activities).

“During my visit the staff were dealing with the residents. I asked the nurse what was the reason that almost all the residents were rocking and she said that they were bored. The day I was there is ‘cleaning day’ (even though there is cleaning every day). Wednesdays they disinfect everything, so on that day residents do nothing during their occupational therapy.” (Hungary)

“Residents spent most of their spare time in the afternoon just sitting, sleeping, pacing, smoking, talking to each other.” (Poland)

“In general, there is an atmosphere of disengagement and residents are bored with everyday routine. The staff is too busy with duties to take any coherent action towards residents.” (Poland)

“Activities are limited and simple; therapy by music, loud reading, sewing, painting. Residents are choosing if they want to participate or not. General policy is not to worsen their physical and mental conditions as they cannot be improved”. (Poland)

Some residents typically left the living unit to take part in activities elsewhere. When asked what those people who were not in the unit were doing at the time, staff reported that in general, people were still somewhere else in the institution.

In Hungary, half of the living units reported people being out at work in the institution; on average, 69% of those outside the living unit were people with low support needs (25% medium and 6% high support needs). Three units reported people being elsewhere in the institution having lunch, smoking or sitting in a communal area; two units reported people leaving the institution to go shopping and one unit reported people walking around the hospital grounds.

Polish living units reported a wider range of activities. Half reported people attending therapy or education sessions on site, nine reported people visiting friends in other living units as well as the kinds of activities already listed. On average, 36% of people outside the living units had low support needs, 55% had medium support needs and 9% had high support needs.

In Romania, seven out of 16 units reported people walking in the institution grounds. Three units reported people shopping outside the institution, two units reported people in a communal area and one unit reported people working. People with low support needs made up 71% of those outside the living unit, with 29% of people having medium support needs. No one with high support needs was observed outside the living unit.

Finally, the researchers noted what staff were doing during the observation period. Table 24 summarises these results. The figures represent the number of units in which each type of staff activity was observed.



## Community Psychiatry in Italy

The process towards the closure of asylums in Italy begun in 1971 by the diffusion of criticism of psychiatric culture. The Trieste S. Giovanni psychiatric hospital, directed by Franco Basaglia, became the great laboratory that started the cultural revolution towards a radical change of psychiatric care, opening the gates of its great park to the community. The doors of the wards were opened. A patient wrote this graffiti on a wall: "San Giovanni is an open hospital: both coming and going".

In 1978, the law 180 sanctioned the end of the Psychiatric Hospital as an institution that removed persons with mental health problems from society and segregated them under prison-like conditions, as they were considered "a danger to themselves and to others and offensive to society". The understanding of mental health problems progressed from a situation where society had erected a protective barrier against afflicted persons, to one in which the person is considered a patient who has a right to be treated, and not simply guarded and segregated. There was a rejection of the concept of mental health problems as something different, dangerous, to be hidden and denied. Psychiatric problems no longer stigmatised the person nor set them apart in psychiatric hospitals located well outside the towns, isolated from society.

The law 180 provided a regulatory framework dealing with three major themes:

- The closing of the psychiatric hospitals.
- The construction of a network of services which would be alternative in real terms, prescribing the nature of the new mental health facilities to be organised on a regional basis.
- Placing the "patient and not the illness" at the centre of the effort to create therapeutic, rehabilitative and emancipatory processes. User -participation in services was used as one of the catalysts for change.

The same law initiated the process of change by prohibiting new admissions to Psychiatric Hospitals. The number of beds in public psychiatric hospitals decreased from over 60.000 in 1978 to 2.500 in 1998. Private clinics witnessed a parallel trend. The number of psychiatrists working in community mental health care has increased considerably from 5% of the entire workforce to 16%. Broad guidelines for the new psychiatric services were prescribed in law:

- Out-patient clinics were established as new departments within General Hospitals
- The Department of Mental Health replaced the administrative structure of the Psychiatric Hospital;
- Admissions to psychiatric wards were no longer motivated by the fact that the patient was "dangerous", but by the need for treatment that could not be provided outside a hospital;
- Admission was therefore solely a measure taken for health reasons;
- Patients were brought into closer contact with normal life and with their families.

The aim of the new mental health structures was to provide differentiated kinds of treatment, to reduce the need for hospitalisation to a minimum and to limit its duration, by means of a network of services for prevention, suitable outpatient and in-patient care, treatment and rehabilitation. The organisational model is based mainly upon the co-ordinated activities of the psychiatric services operating within one geographic area, in accordance with the principle of therapeutic continuity.

The ministerial decree of 1998 stated the definitive closure of Psychiatric Hospitals imposing economic penalties on those regions which delay its implementation. By the end of 1998, the last 15,000 patients (in the 70's there were 120,000 inmates) still living in 57 Italian psychiatric hospitals were resettled to residential facilities and family groups. In fact, at the end of 1998, the Minister of Health was able to announce the definitive closing of psychiatric hospitals in Italy. Mental health centres (whose number increased from 226 to over 4.000 between 1978 and 1998), emergency psychiatric units in general hospitals, residential communities or living groups are now widespread and much more accessible.

This revolution has obviously not been easy to carry out and, still today, there are ideological and practical problems impeding its full implementation. The Italian situation, with its regional and community "deregulation", might appear confused. And yet, it guarantees that a person with mental health problems is treated as a citizen in all respects; that he always be considered as a person, a subject, and an individual.

### 3 Discussion of the results

This study is the first attempt to compare institutions for disabled people in different European countries using the same methods and measures. Its findings are, of necessity, exploratory. It is not possible to determine the adequacy of the sampling strategy given the lack of information about the number of institutions and their characteristics in each country. The financial constraints under which the project was conducted also meant that it was not possible to include sufficient checks on the inter-rater reliability of the data or on the validity and accuracy of some interview responses. Nevertheless, the study provides, for the first time, a large amount of broadly comparable data about institutions in four countries and presents a relatively clear and consistent picture.

The general finding of this project is, that in many respects, large residential institutions in these four countries are similar to those that have been studied elsewhere. People – especially those people who need most support – often live lives characterised by hours of inactivity, boredom and isolation. Staff numbers are frequently too low to provide habilitation, rehabilitation and therapy. The physical environment is relatively impersonal and does not provide the kind of privacy and homeliness that the general population would expect. Contact with family, friends and community is limited. In this situation, where the organisation becomes relatively isolated from the wider community, practices develop that should be unacceptable, such as keeping people in bed all day or the use of cage beds to confine people.

There is considerable variation between the different kinds of institution studied. In some respects French, and sometimes Polish, institutions achieve better results – for example in terms of the number of people sharing living rooms, where French institutions have half the number of Polish institutions and

a third to a quarter of those in Hungarian or Romanian institutions. French institutions were rated as more homelike than the others. In other respects (for example, the number of residents receiving weekly contact from their family or going out to visit friends, or the number of living units without partitions and doors in toilets) French institutions are similar to those in the other countries studied.

In comparison with community-based services, in which people live either in small group homes or their own housing, dispersed in the community but with adequate staff support for their needs, the services studied here generally perform rather less well. For example, the assessment of the ‘homelikeness’ of living units in this study found mean scores of 2.85 out of 5 for France, 1.45 for Poland, 0.55 for Romania and 0.49 for Hungary. A recent study of dispersed housing in the community for people with intellectual disabilities in the United Kingdom found a mean score on the same measure of 4.3<sup>25</sup>. Staff ratios are typically much higher in community-based services for people with more severe disabilities. Recent British studies of services for people with severe intellectual disabilities show resident/staff ratios of 0.6<sup>26</sup> and 0.7<sup>27</sup>, compared with 1.4 to 14.0 found in this study (see Table 17 above).

Differences in the location and type of accommodation, and in the staffing and organisation of community-based services, are reflected in the outcomes experienced by service users. For example, the scores for community involvement reported in this study (see Table 21 above) range from 2% (Romania) to 21% (France); equivalent results from community-based services are 43% (England) and 47% (Scotland)<sup>28</sup>. A study of residents in community-based services for people with mainly high support needs and intellectual disabilities in England,<sup>29</sup> showed that 62% of people observed were engaged in meaningful daily activities compared to 5-

<sup>25</sup> Emerson et al., 1999

<sup>26</sup> *ibid.*

<sup>27</sup> Mansell et al., 2003

<sup>28</sup> Ager, Myers and Kerr, 2001; Raynes et al., 1994

<sup>29</sup> Mansell et al., 2003

27% of those living in the institutions in this study (see Table 23 above).

These findings are generally supported by other studies of community-based services in Britain<sup>30</sup>, Sweden<sup>31</sup>, Norway<sup>32</sup>, North America and Australia<sup>33</sup>.

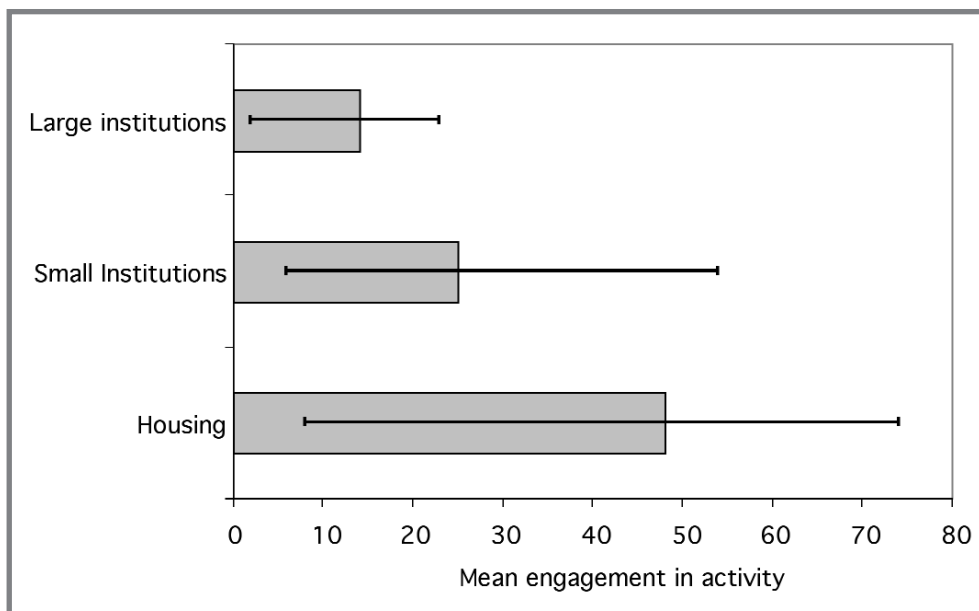
Of course, community-based services also vary in their quality and this has been a source of concern to commentators<sup>34</sup>. A review of all British studies of de-institutionalisation and community living carried out by Emerson and Hatton (1994) illustrates the variation between services on a range of different measures. Their data shows that the ranges of scores on different measures overlap considerably between large institutions, small institutions and housing-based services. Figure 1 presents the mean level of engagement in meaningful activity found in these three types of service,

together with the ranges. The data is drawn from 46 studies of 2,350 people.

The considerable overlap in the ranges of scores indicates that better large institutions can produce outcomes as good as weaker small institutions; and that better small institutions can achieve outcomes as good as weaker supported housing. However differences in the means indicate that, on average, community-based services are the best option.

In some countries (such as Sweden, Denmark and Norway), the replacement of institutional care by supported housing in the community has been a matter of principle. In Britain, where the empirical basis for the policy has been contested, variability on the performance of community-based services has been the subject of a sustained research effort. There is evidence of differential effects of community-

**Figure 1: Resident engagement in three types of service<sup>35</sup>**



<sup>30</sup> Shepherd et al., 1996

<sup>31</sup> Ericsson, 2002

<sup>32</sup> Tossebro, Gustavsson and Dyrendahl, 1996

<sup>33</sup> Allen, 1989; Kim, Larson and Lakin, 2001; Young et al., 1998

<sup>34</sup> Landesman, 1988; Mansell, 1996

<sup>35</sup> data from Emerson and Hatton, 1994

support for people with different kinds of disability or support needs. For example, people with challenging behaviour are more likely to be re-institutionalised after placement breakdown. However, pilot projects for demonstration purposes have shown that it is possible to serve people with the most complex needs in the community with beneficial effects<sup>36</sup>. Rather, it is variation in staff performance that appears to be the critical factor in explaining differences in outcome<sup>37</sup>.

Thus the overall picture that emerges from research is that

- (i) on average, community-based services offer better outcomes than institutions in terms of quality of life for disabled people;
- (ii) replacement of institutions by community-based alternatives provides opportunities, but does not, in itself, guarantee better outcomes – it is a necessary but not sufficient condition;
- (iii) achievement of good outcomes in community-based services depends on the quality of staff support available to disabled people.

#### **4 A study on the legal and financial basis of residential services**

The “Included in Society” project has asked the European Association of Service Providers for People with Disabilities (EASPD) to conduct a study on the legal and financial basis of residential services in Europe. The detailed report of this study is provided in Annex II. The following tries to summarise and analyse the results.

The legal and financial frameworks under which residential services for people with disabilities are organised and regulated are, on the whole, very complex and vary greatly in different countries. Different historical, economic, social and political conditions determine the way the sector looks today.

#### **Organisation and funding of residential services**

The research demonstrated that responsibilities in the field of service provision differ according to the country. Furthermore, there are very different national and local policies and legislation concerning service provision for disabled people. At European level, EASPD identified about 190 guidelines which could, in one way or another, affect the disability sector in the member states.

The study concluded that residential settings for people with disabilities are regulated by laws which are often outdated and not always directly related to the provision of residential services for people with disabilities.

In some countries, recent trends in government policies and measures seem to favour the creation of, and the shift towards alternatives to residential care.

#### **Barriers identified by service providers**

A general finding is that, in most countries the legislation governing this sector is quite old. Recognition and organisation of support services are still based on regulations which reflect the old medical approach and do not allow any flexibility. This is one of the reasons why they do not provide an adequate framework for organisations that need to respond to the current needs and wishes of people with disabilities and their families. The presence of new legislation, however, does not necessarily guarantee that, in practice, service provision follows it.

A number of service providers report the following barriers regarding the legal measures that apply to them and to the disability sector:

- Laws that are no longer in force still continue to guide practice.
- New laws attempt to implement new systems but there is no adequate funding available.
- Implementation is far behind legislation.

<sup>36</sup> Felce et al., 1998; Hatton et al., 1995; Mansell, 1994; Mansell, 1995

<sup>37</sup> Felce, 1996; Felce and Emerson, 2001; Mansell et al., 2003



In some countries in Central and Eastern Europe, community-based services exist only as small and isolated programs. It will take a more global and holistic approach to make permanent and efficient changes. Furthermore, there is limited public awareness in these countries of institutional practices and current research into community-based alternatives.

Some countries reported a move towards personal budgets in the financing of services. Service providers identified the following possible problems with individualised budgets:

- Position of the client as an employer.
- The needs of the client group are less visible to political and public scrutiny. There is no control on what they use the money for and what their needs are.

The discrepancy of opinions and views of the different stakeholders like disabled people, parents, professionals and policy makers also

creates problems. Service providers believe that sometimes, the reluctance of parents to make the decision for their children to live in a community based environment, as a result of their own fears, could lead to certain patterns of developments based on wrong assumptions.

Long waiting lists for services are a problem which is often misinterpreted and used as an excuse to invest in existing (large) residential facilities. Research has shown that the existence of long waiting lists is often misinterpreted as a big interest in the type of services for people with disabilities currently offered and that this is used as an argument for the extension of the capacity of these large residential settings.

It is also necessary to restructure the organisation of support services and to provide incentives for service providers to set up community based services

### **Promoting the transfer towards community based and inclusive solutions**

Based on the research results described above, EASPD has proposed the following action points:

#### **Provide real choices for people with disabilities**

Legislation needs to put the choice of the persons receiving the service and their relatives at the heart of every process of service recognition. This way, only those services, which have proved to meet the needs of clients, would exist. Choice must be integrated as an essential concept in legislation in order to re-organise services for people with disabilities. This will facilitate and fuel the process of change towards more person-centred services.

#### **Introduction of person-centred financing or personalised budgets**

Persons with disabilities or their families should have a choice in how they wish to receive support and in how they would like to spend or receive their benefits and

budgets. The introduction of personalised budgets is one of the most popular solutions by far to guarantee the 'personalisation' of support packages. With the introduction of personalised budgets, however, support must always be available for persons with disabilities to deal with employer issues and administration.

#### **Simplify the legislative framework and clarify the roles and responsibilities**

The identification of clearer roles for organising and financing bodies as well as clarity over the methods of allocating and receiving benefits would help parents and persons with a disability to become better informed about their entitlements. The creation of a body to offer disabled people and their families clear advice and information would be a big step towards a transparent process.

**Avoid re-investment in existing large-scale solutions** in an attempt to solve the problem of large waiting lists. Thorough research on the current availability and adequacy of service provision needs to be undertaken in order to develop a constructive long-term vision.

**Equal conditions for state financing or financing from other authorities** for the different kinds of residential settings.

**Support private, community-based initiatives**, as examples of models of good practice, in a sustainable and structural way.

**Avoid newly-constructed large buildings to accommodate persons with special needs.** Subsidies for the construction of new buildings in the disability sector should be strictly regulated and only allowed for small-scale community based settings.

**Invest in training for social care staff** focusing on providing support in mainstream and community-based settings.

**Make procedures transparent and simplify bureaucratic rules** for services that want to







proceed towards de-centralised and small-scale units. Plans for re-structure or re-construction as part of a move towards community-based units should receive a more favourable treatment and procedural barriers should be limited to a minimum.

**Adapt current legislative standards** for disability services (e.g. fire prevention, rules on hygiene and environmental issues, etc.) to allow small-scale settings to be organised.

**Offer individualised solutions instead of total packages of care** through separation of different support areas like residential support and support for daily living.

**Overall management and financial plan**

The above recommendations should be part of an overall action plan. The action plan should include concrete short-term and long-term objectives and mid and long-term reviews.

## Disabled people want to live as equal citizens



To make it possible to achieve the vision of disabled people living as equal citizens included in society, various goals need to be established. These goals describe what needs to be achieved in the long-term.

In the future, disabled people should have the same opportunities as other citizens to exercise their rights and participate fully in the society in which they live. They should have access to comprehensive, high quality community-based alternatives to institutional care. All stakeholders should be involved in establishing these services, which are designed and provided on the basis of individual needs. The principles for positive change are central to any action taken in relation to planning, providing and reviewing community-based services. Furthermore, advocacy and peer support should be ensured and promoted.

The ultimate aim is that people with disabilities can live as equal citizens, with full respect for their human rights, have choice in their daily lives and have real opportunities to be independent and to actively participate in their communities.

In order to achieve this aim, various goals need to be established. These goals seek to describe what needs to be achieved in the long-term. Having decided on the goals, the action which needs to be taken in order to reach these goals should be planned and implemented. This Chapter suggests six goals which describe how residential services should look in the long-term. In Chapter V, the project goes on to develop six priority areas for action in order to achieve these goals.

The project partners describe their vision for the future as follows:

### **1 Disabled people have the same opportunities as other citizens to exercise their rights and participate fully in the society in which they live.**

The public expect, and laws and policy require, that disabled people have the same opportunities as other citizens to exercise their rights and participate fully in the society in which they live. In order to be able to participate fully in community life, disabled people must have equal access to the range of services available to other citizens such as housing, education, transport, employment and leisure. They must also be able to exercise their human rights, such as the right to vote, the right to liberty and the right to private and family life.

### **2 Comprehensive, high quality community-based alternatives to institutional care are available and accessible to all disabled people**

A clear plan for the development, provision and review of community-based services should be agreed by the individuals and organizations identified as having an interest or involvement in the development of community-based services. Such plans must demonstrate that the provision of services is based upon each individual's needs and preferences (a 'needs-led' approach), be aimed at promoting the person's independence, as far as possible, and must recognize that some individuals will have greater and/or more complex support needs than others.

### **3 All stakeholders are involved in establishing appropriate community-based services**

The key to creating change is to establish a real partnership between all individuals and organizations that have interest and/or involvement in providing support to disabled people. Key stakeholders will be disabled people, their families, service providers including their staff, health and care professionals, NGOs working in the disability and human rights field, policy makers and politicians.

### **4 Services are designed and provided on the basis of individual needs**

Services which are provided on the basis of the needs of persons with disabilities, must determine the way support arrangements will look in the future. Services will be geared towards the needs of each person rather than individuals being expected to make do with the services that are available.

#### **Community living in Slovakia**

The Land of Harmony Foundation<sup>38</sup> in Slovakia provides two small flats for one woman and four men with physical and learning disabilities. All of them are living, for the first time, independently from family or an institution with the support of social workers and the local community. They are able to make decisions about all aspects of their lives: what to eat, what to buy, how to spend the money, what to do, where to work, whom to meet, etc. The individual approach, trust and the principle of providing support only when needed, make this service exceptional in Slovakia. When the clients make mistakes, these are considered to be learning opportunities for them.

<sup>38</sup> Contact: Agentúra podporných služieb, Predmestská 24, 0101 01 Žilina, Slovakia. [nkh@slovanet.sk](mailto:nkh@slovanet.sk)



## **5 The principles for positive change are central to any action taken in relation to planning, providing and reviewing community-based services**

The principles of respect, choice, participation and independence must be key to all work that is undertaken. In addition local/regional agencies must accept that they are responsible for the provision of community-based services to disabled people living in their communities.

## **6 Advocacy and peer support is ensured and promoted**

Advocacy activities should be developed among disabled people as to ensure that their voices get heard. Advocacy activities (including self-advocacy) enhance involvement of disabled people at all level of the society and help other people to realise that there is no limitation to their participation in the society.

## The closure of institutions in England and Wales

Alternatives to institutional care in Britain began to be seriously considered in the 1950s when the demand for residential care appeared to be steadily increasing. A Royal Commission recommended that more provision should be made for people with mild intellectual disabilities in residential homes in the community, partly in order to relieve pressure on hospital places. The responsibility for community services lay with local, rather than central, government and little was done until, in the mid-1960s, a series of public scandals in institutions revealed extensive ill-treatment and neglect in squalid, over-crowded surroundings. In response to this a Government White Paper reinforced the goal of providing community services for people with mild or moderate intellectual disabilities, and set unusually clear targets for local authority services. This initiative applied to England and Wales, Scotland has a different legislative framework.

Also at the beginning of the 1970s, a new lobby, for the first time, called for the complete abandonment of hospital care and its replacement by housing-based services in the community. This lobby drew its inspiration partly from the first community services in the United States and Scandinavia. In the early part of the 1970s, most new developments in the community were of large (20--25 person) units including some for people with severe and profound intellectual disabilities. By the middle of the decade, however, there was increasing pressure for housing-based services for all and the first examples of supported housing for people with severe or profound intellectual disabilities appeared.

Policy in Wales and England diverged at this point. In Wales, criticism of institutional refurbishment led to a demonstration project to serve a whole sector of the city of Cardiff with community-based services. The shift in thinking this entailed was later reflected in a national policy of developing community-based services and closing institutions. Review of this policy after a decade showed substantial development of community services by local authorities using earmarked central government funds, though with little impact on institutional numbers. In the second decade closure was identified as a key priority.

In England, the main policy initiative in the 1970s focused on transferring funds from the health service (responsible for institutions) to local government. By the beginning of the 1980s, another official committee had recommended housing-based services as the main future model of care and several reports outlined the necessary elements of community services. These initiatives were followed by a national demonstration project that signalled central government's overall acceptance of the policy goal of de-institutionalisation and gave many local service agencies experience of the work involved. In the second half of the 1980s the first large-scale institutional closures happened and the process gathered momentum, with de-institutionalisation becoming tacitly accepted as a general policy goal.

Also in the mid-1980s, there were policy developments concerned primarily with services for old people and people with mental health problems. Official concern about the rapidly increasing number of old people entering residential care funded by social security, and evidence that there was considerable inefficiency, led to several reviews. From these, came major legislative reform in the 1990 Health and Community Care Act. This began to close the social security funding route and to impose on local authorities, the responsibility for funding residential care. In future, hospital care was to be almost solely concerned with short-term treatment. A further innovation was the requirement that, in future, most residential services purchased by local authorities were to be run by private sector or voluntary organisations.



# Policy and priority actions for quality residential services for disabled people in Europe

To achieve the goals for community living and the availability of comprehensive and high quality community-based services for all disabled people across Europe, the “Included in Society” project proposes six policy priorities:

- I. Develop policies and action plans for the provision of community-based services that respect and promote the human rights of disabled people
- II. Provide, as a priority, community-based services for disabled people in the new member states and accession countries
- III. Establish compulsory systems of quality monitoring and assurance as well as accessible complaints mechanisms
- IV. Establish financing arrangements that ensure services are provided on the basis of individual needs
- V. Commit to stop the building of new large residential institutions in Europe
- VI. Establish the “European Coalition for Community Living” as a European monitoring and action centre for the provision of community-based services in Europe

Community living and comprehensive, high quality, community-based services require the identification of realistic and effective policy priorities. Such priorities can assist the individuals, organizations and government bodies involved in this work to agree a plan of action for the development and provision of community-based services as alternatives to institutional care.

The “Included in Society” project therefore proposes six policy priorities for the coming years. The following section describes what steps should be taken in order to meet the six key priorities.

### 1 Develop policies and action plans at local, national, European and international level

The existence of policies and action plans at local, national, European and international level that respect and promote the human rights of disabled people is essential for the provision of more and better community-based services. Priority action should be taken in five areas:

#### Action 1.1 Protect and promote the rights of disabled people

People with disabilities are equal citizens of their countries and local communities with the same rights as any other citizen, including the right to participate in society. These rights are often violated in large residential institutions where the residents face serious human rights abuses and are segregated from society.

Governments, and the European Union must ensure that all their policies and legislation comply with international human rights instruments such as the European Convention on Human Rights, the European Social Charter and the Convention against Torture and Degrading Treatment. They must ensure that there are effective remedies if individuals' rights are violated. This means that there must be sufficient monitoring and inspection of premises where disabled people are receiving residential care and appropriate action taken if human rights violations are suspected. This includes the prosecution of the persons responsible and closing down an institution in cases of serious and persistent human rights abuses against any of the residents.

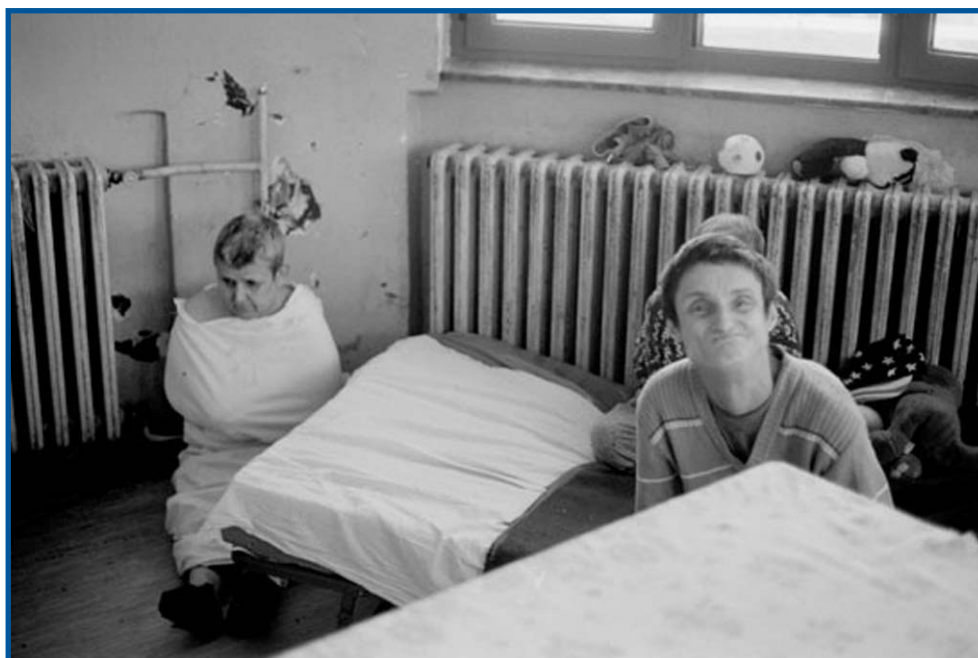
**Action 1.2**  
**Mainstream disability policy at all levels**

In many countries, the responsibility for developing and implementing policies in relation to disabled people is left to only one Ministry, Department or Unit. However, all policy fields, including education, employment, transport or housing, are relevant to disabled people.

In accordance with the Council Conclusions evaluating the European Year of People with Disabilities 2003, the "Included in Society" project therefore calls upon all levels of government and administration to include disability policy in their work (i.e. to 'mainstream' disability policy). This applies especially to education, employment, health and social policies. All such policies must be complementary in order to provide seamless services for the inclusion of disabled people in the life of society. A co-ordination of the different policy fields can be achieved by the creation of a national co-ordinating body which could also provide the necessary information to disabled people and their families with regards to accessing services, benefit entitlements etc.

It is essential to involve disability organisations and family carer's groups in all policy development and to promote advocacy activities (including self-advocacy). This enhances the involvement of disabled people at all levels of society.

The European Commission has the special responsibility of ensuring that the rights and inclusion of disabled people are addressed in all European policy areas, especially in the







policies working to combat social exclusion and discrimination, but also in consumer policy, health, employment, education and youth policy.

### **Action 1.3 Establish and implement Action Plans**

Experiences from countries or regions having successfully implemented comprehensive de-institutionalisation policies show that long-term planning of measures at different levels is a necessary prerequisite for success.

Therefore, the project “Included in Society” calls upon governments, local authorities and service providers at all levels to develop and implement comprehensive Action Plans for the transfer of service provision from large residential institutions to community-based services. All Action Plans should be accompanied by strong monitoring mechanisms that ensure timely and complete implementation of the planned activities.

Action Plans should be developed with the involvement of all stakeholders and should ensure that they address all disabled people, including those with the most complex support needs.

The same applies at European Union level where Action Plans in different areas should clearly make reference to the situation of disabled people in large residential institutions.

### **Action 1.4 Launch a European Awareness Campaign**

There is very little public awareness about the serious adverse effects of institutionalisation on disabled users and their families. Similarly, few responsible decision-makers in local authorities, organizations or policy understand the seriousness of the situation, nor are they aware that public spending on care in large residential institutions does not provide a reasonable quality service for the users.

The “Included in Society” project therefore calls on the European Commission to launch a Europe-wide awareness campaign targeted at decision-makers in administrative bodies organizations and policy. This campaign should focus on combating social exclusion, discrimination and negative attitudes towards disabled people and should also promote community-based services. It should inform decision-makers about existing research and models of good practice in order to stimulate more action in the Member States.

**Action 1.5**  
**Reinforce the UN Standard Rules and develop an appropriate UN Convention on the Rights of People with Disabilities**

Governments, as well as the European Union and disability organisations are called upon to reinforce the important UN Standard Rules on the Equalisation of Opportunities for People with Disabilities as a guidance document for their work in the disability field. They are also asked to make sure that the discrimination and social exclusion caused by large residential institutions is outlawed by the UN Convention on the Human Rights of Disabled people that is presently being developed.

## **2 Community-based services in the new member states and accession countries**

Research and reports from many experts and organisations, including Amnesty International, the European Disability Forum, Inclusion Europe and the Open Society Mental Health Initiative, confirm that large residential institutions are very prevalent in the new member states and accession countries. In some institutions, serious violations of Human Rights have been reported. Very few of the institutions are able to provide quality, personalised services. This situation provides justification for special attention and action.

**Action 2.1**  
**Local responsibility for disabled citizens**

The systems of institutional care in most new member states and candidate countries has led to the random placement of disabled people in institutions throughout the country, regardless of their place of origin. Many of the institutions are situated in remote and inaccessible parts of the country. Often this means that residents lose contact with their family and local community.

All local governments and administration in the new member states and candidate countries should therefore accept their responsibility to provide services for all disabled people within their communities. They should be prepared to return those disabled people who have spent their lives in institutions in other regions of the country, to their place of origin. The national governments should enforce and support this policy, through funding and other assistance.

**Action 2.2**  
**Equal access for NGOs to provide quality community-based services**

In the new member states and candidate countries, residential services for disabled people are mostly provided by the State, regional or local administrations. In many countries there are legislative and financial rules that make it difficult for NGOs to provide community-based services. If NGOs can provide services, they often receive less financing per service user than the providers of large institutions do although they provide equal or better services

National governments must create laws and administrative conditions that link the financing of residential facilities to their capacity to answer the individual needs of the users and to the quality of life they provide. In this way, NGOs will enjoy equal opportunities to provide quality community-based services.

### **Action 2.3**

#### **European Union funding for community-based residential services in new member states**

The creation of community-based residential alternatives to large institutions will also require investments in infrastructure, training and human resources. Without this investment, the Human Rights of disabled people remain endangered. In the present difficult economic situation of most new member states, the European Structural Funds could be a very important resource for providing the necessary financial means.

The governments of the new member states are called upon to establish from within the EU funding allocated to them, a dedicated budget for financing new community-based services in their countries. The European Parliament, the European Commission and the disability movement should remind the new member states of their responsibilities and ensure that European funds are made available for this purpose. EU funding should never be used to improve existing large institutions, since this would mean investment into the old system<sup>39</sup>.

## **3 Establish compulsory systems of quality monitoring and enforcement**

### **Action 3.1**

#### **Address disability issues in the framework of consumer protection policy**

Very few countries already include the provision of residential services for disabled people in their consumer protection policies. However, disabled people are consumers of the support they receive and residential services they use and must therefore be protected within the framework of mainstream consumer policy.

National and European consumer policy must therefore address this issue and develop

adequate and effective measures of consumer protection and information for disabled people in residential services. Special attention must also be paid to the establishment of complaints procedures that are accessible for disabled people living in large institutions.

### **Action 3.2**

#### **Establish systems of quality monitoring oriented to the quality-of-life of the user**

It has been demonstrated by the research of this and other projects that there are no simple indicators for the quality of a residential service for disabled people. While in general, the quality of smaller residential services tends to be better than those of larger institutions, this is not always the case. This shows the limitations of input indicators, such as the size of rooms, the staff/client ratio, etc., as good scores in those do not always guarantee a good service quality for the user. The indicator of the quality of any service provided must therefore be the outcome in terms of the quality-of-life of the users of that service.

The project therefore calls upon national governments, and the European Union to install compulsory systems of quality monitoring of residential services based on indicators related to the quality-of-life of the residents. These systems must be based on the involvement of users, their families and their representative organizations in the monitoring process. The European Union should allow comparability across Europe by providing a typology of the standards for residential services.

### **Action 3.3**

#### **Connect financial and administrative consequences to quality monitoring**

Quality monitoring is most effective when financing and administrative consequences are linked to its outcome. National and local governments must ensure that the consequences for bad quality services are immediate and effective. Services with an outstanding quality should be supported and receive incentives.

<sup>39</sup> Eventually necessary emergency financing with humanitarian objectives, e.g. the renovation of a heating system, should be financed from national budgets.



Consequences of quality monitoring might include:

- A decision to close the service within a fixed period of time.
- Legal action against the provider or individual staff members.
- Consequences for the service-providing organization, for example, black-listing.
- Preventing any further admissions, thus reducing the number of clients.
- Administrative measures, for example change of management of the service.
- Provision of additional financial support in order to improve the service<sup>40</sup>.
- Incentives for high quality services.

#### **4 Establish financing systems based on individual needs**

It is crucial to establish legal and financial frameworks that enable the provision of services to be based on the needs of each individual and not on the convenience of those planning or providing such services. The legislation and financial mechanisms for the

transfer of resources to high quality community-based services should ensure that these new settings are located both in rural and urban areas according to the needs of people using the service, wherever they live.

It will, however, be important to maintain the principle that the states are responsible for financing and securing quality services for all their citizens.

##### **Action 4.1 Promote the principle of needs-based financing**

Every disabled person must have the right to the services and support she or he needs. However, it is still common practice to allocate resources independently of the needs of the users, but as global subsidy per person receiving the service.

The project calls upon all European governments to establish the principle of budgets allocated on the basis of the needs of each individual user. The process of

<sup>40</sup> It must be ensured that additional financing is under no circumstances provided to residential institutions which cannot be fundamentally changed, e.g. because of existing infrastructure, values of the service provider, history of operation, etc.

resource- allocation must be transparent and must be undertaken in cooperation with disabled people, their families and their representative organizations.

#### **Action 4.2 Establish systems of personal budgets**

In most European countries, governments still tend to finance providers of services. However, there is a strong movement in Europe towards giving more control to the users themselves by linking financing to them, rather than to the services. Such a system exists for example in the Netherlands, the UK, Belgium and Germany and ensures that the money follows the user, whichever service the user wants to use.

All European governments are encouraged to establish financing systems for services in which the financing is linked to the users and gives them control about how their support needs can be satisfied.

#### **Action 4.3 Create independent systems for user support**

In a system of personal budgets, it is crucial to establish dependable systems of independent user-advice and support. This is necessary both to support the user and the family in making difficult decisions and to protect the user from exploitation or coercion by others.

The project therefore calls on governments and the European Union to strengthen user organizations in order to support them in the establishment of counselling services for users of personal budgets.

### **5 A commitment to stop the building of new large residential institutions in Europe**

Halting the building of new institutions for disabled people is one of the most important immediate objectives. Each new institution is an

investment in the old system, since it ties down finances and staff for decades and perpetuates the problems rather than solving them.

All governments, service providers and NGOs in Europe are therefore called upon to publicly subscribe to a Commitment to stop the building of new institutions in Europe. The text of the Commitment and possibilities to endorse it can be found in all European languages on the website [www.community-living.info](http://www.community-living.info).

#### **Commitment to Stop the Building of New Large Residential Institutions in Europe**

The signatories to this Commitment undertake, on behalf of their organization, political body, administration, company or government that they will not finance or otherwise support the establishment of new large residential institutions for any group of disabled people.

They commit themselves to ensuring that any new residential service for disabled people in their remit complies with the following basic quality standards:

- Location within a local social community
- Possibilities for interaction with the local community
- Respect for the personal space, privacy and property of each user
- Availability of the necessary personal support for each user

### **6 The European Coalition for Community Living**

The project “Included in Society” has demonstrated that the problem of institutional care for disabled people is prevalent in many European countries and that long-term action is necessary to solve it. The development of the situation must be constantly monitored and brought to the attention of European decision-makers and the public.



The four managing partners of the “Included in Society” project, Inclusion Europe, Autism Europe, Mental Health Europe and the Open Society Mental Health Initiative, will therefore create a European Monitoring and Action Centre and will invite all organizations concerned about the de-institutionalisation process to join. On the basis of the existing

data on almost 2.500 institutions for disabled people in Europe, the Monitoring Centre will promote community-based residential services, monitor the development of the situation and cooperate with all subsequent European research, training or exchange projects in this area.



# All stakeholders work together in the creation of community-based alternatives

This part of the report highlights some of the actions to be undertaken by the different actors and decision-making bodies in order to ensure the creation of quality community-based services as alternative to large residential institutions in Europe. All stakeholders - disabled people, their families, service providers, disability organisations and authorities - should work together to reach the same goals and objectives in respect to the establishment of community-based alternatives to institutions.

While the creation of community-based alternatives requires the commitment of many different actors, national governments remain responsible for providing quality services to all their citizens.



### 1. National and regional governments

The change from an institutionalised to a community-based model of service provision for disabled people requires significant political will and leadership. Countries in which institutions still exist, have to change a system that has existed over more than 50 years, together with the mentality of staff and administrations.

However, following the principles of good governance and Human Rights, governments



have to provide quality services and support to all their citizens. To confine one group to a life outside the rest of society is no longer acceptable in modern European society.

The “Included in Society” project suggests several initiatives in national policy development that will lead to better services for disabled citizens.

### **1.1 Changing policy at national level**

National disability policy must be developed and implemented in close cooperation with disability organisations and family carer’s groups. Disability policy should be mainstreamed in all policy areas so as to ensure that disabled people can participate in normal life of society to the greatest possible extent.

National governments should observe the following fundamental principles:

- Human Rights for all citizens and the strict implementation of these rights.
- The right of disabled people to inclusive, quality services.
- The principle to provide financing only to quality services.
- A realistic needs-assessment for services.

Governments should pass legislation allowing the allocation of budgets on the basis of the needs of each individual user. The process of resource-allocation must be transparent and be undertaken in cooperation with the users, their families and their organizations. Governments should also establish financing systems for services in which the financing is linked to the users and gives them control over how their support needs can be satisfied.

A major prerequisite for mainstreaming disability policy is good, specialized co-ordination of mainstreaming efforts. Countries should establish such coordinating mechanisms that coordinate mainstreaming, initiate action, train experts and policy-makers.

Good, reliable statistical data and databases are also prerequisites for a mainstreaming approach. No evidence-based policy-making can work without those.

### **1.2 Putting the policy of de-institutionalisation into practice**

In many cases studied in the framework of this project, de-institutionalisation policy has been adopted by national governments in the form of a declaration. However, little seems to have been done in terms of practical implementation of de-institutionalisation.

Therefore, the “Included in Society” project calls upon all national governments to support their policies with clear Action Plans. These should detail clear and measurable goals in the establishment of community-based alternatives and the closure of large, residential institutions. A strong monitoring mechanism, both internally and externally, should complement these Action Plans.

A central body offering guidance for disabled people, service providers and staff should be created. This body could ensure a coordinated approach and be involved in monitoring the implementation of the Action Plans.

### **1.3 Change financing and administrative structures**

A key step to be taken by authorities in order to adapt to the new requirements by people with disabilities and their families is to identify available resources for innovation and transition. It is especially important to evaluate the financial costs involved in the creation of community-based services that provide the necessary technical and qualified assistance to all persons with disabilities.

Financing and administrative structures should determine the long-term financing of community-based residential services. Governments should note that such planning and investments in buildings and infrastructures will have long-term consequences.

Governments should identify and/or transfer resources currently available towards the creation of independent living schemes. Direct payment schemes and new forms of support, such as individualized budgets should also be foreseen by governments as a way to ensure high quality and professional support.

Defining clearer roles of organisational and financing bodies and the different ways to allocate and receive benefits and allowances would help disabled people and their families to be better informed about their entitlements.

Investments in existing large-scale solutions as attempts to solve the problem of large waiting lists should be avoided. Subsidies for the construction of new buildings should also be strictly regulated and only allowed for small-scale community-based settings. Community-based initiatives of NGOs should be promoted as models of good practice in a sustainable and structural manner.

It is also important to make procedures transparent and to simplify bureaucracy for services that want to proceed towards decentralised and small-scale units.

#### 1.4 Quality control and assurance

One of the concerns for governments is that the limited budgets in the fields of social security and support are already well spent and are used for the highest possible quality of services. It is therefore in the interest of governments to contract service provision for people with disabilities to those organizations which are able to provide a verifiable quality of services.

This thinking must be propagated throughout all governmental services and decision-making processes. It is a very important task of governments to promote this philosophy and to analyse, for all services, whether the best possible quality is being provided by the funds available (see page XXX for research comparing costs per place in institutional and community-based services).

One of the most important issues in ensuring the establishment of community-based residential services is a strict and binding system of quality control and assurance that is clearly linked to financial consequences for service providers who fail to pass the quality criteria. It is absolutely necessary that this quality control and assurance is led by disability organizations and focuses on the quality of life indicators based on the outcome for the residents. A concentration only on input indicators, like equipment, numbers of places, or staff qualifications, is not adequate because input indicators do not have a direct and linear connection to the resulting quality of life of the residents.

#### ***Nueva*: Evaluating our own living spaces**

*Nueva* is an innovative evaluation method to oversee and certify the quality of the housing offered to people with intellectual disabilities. *Nueva* is run by the organisation ATempo in Austria in the cities of Graz and Vienna.

Among the evaluation methods currently used in this field, *Nueva* is distinctive and particular because it is carried out by people with intellectual disabilities themselves. *Nueva* operates from the point of view of the residents: the criteria and questions are addressed to people with intellectual disabilities based on their own experience and needs as residents. More than 20 *Nueva* training partners have worked together on this method for the last two years.

In order to evaluate the living standards of a living facility, *Nueva* addresses questions to at least 50 % of its residents. The questions are either asked verbally, or in the form otherwise required by each individual. (easy-to-read text, etc.). Based on the results of these questionnaires, *Nueva* publishes a catalogue describing the different living facilities existing for people with different needs (severely

disabled, blind, deaf people, etc.). Moreover, the results are also intended to be used as benchmark data by housing providers. In this way, *Nueva* offers many possibilities for service providers to optimize the quality of their services and to improve their management practices as well as the quality of the information that they supply to their potential clients.

Upon completion of the enquiry the results are analyzed in order to develop a quality profile of each house. The evaluation process ends with two presentations: an extensive one for the service providers and another in easy-to-read format for their clients. *Nueva* experts give advice on housing both to people with learning disabilities and to service providers. In addition, *Nueva* also offers supported employment- and training possibilities in housing-advice, to people with intellectual disabilities.

People with a disability should have the legal right to participate in the implementation of quality monitoring of the services that they are using. Disabled people, their families or independent advocates of disabled people should be able to contribute to decisions regarding the services they are using regardless of any potential adaptation or support they might need to express themselves.

In order to control and implement quality control at national level, the establishment of national agencies for quality control and development is recommended.

### **1.5 Clear and realistic service planning**

Clear planning at every political level is essential to ensure a smooth development process towards quality services and support to disabled people. The roles of all government departments and other agencies should be defined in a planning document, including all relevant Ministries as well as local governments. Planning should not only

focus on building new services, but also on ensuring the provision of relevant staff training, awareness raising campaigns and quality control management.

Governments should be aware that the life expectancy of disabled people is increasing continuously in all European countries. This will especially be the case in the new member states and accession countries as soon as the medical care and living conditions of the population as a whole improves. Better medical care systems will also lead to more people with severe and profound disability surviving beyond childhood and thus requiring services for a longer period of time.

It is therefore vitally important for governments as well as for disability NGOs and service providers to work in co-operation to develop a realistic projection of the number of people with disabilities requiring housing and/or support services. A National Disability Database can provide important information in this regard.

However, in many countries, the need for more community-based services is quite obvious. Therefore, governments should not wait for statistical data, but start, without delay, with the provision of financing and legal conditions for more community-based housing options for disabled people.

Governments should consult with key stakeholders in the planning process of community-based services. A dialogue needs to be initiated between the State, persons with disabilities, service providers and experts from the disability field towards the creation of a new system of high quality, cost-effective support services.

### **1.6 Supporting the families**

The role and importance of parents and family for a disabled person will change as the person grows older. While children and young people with disabilities should live at home with their families, adults with disabilities should – like other adults – no longer live in the family home. However, to adults with

## The situation in Denmark, Finland, Iceland and Norway<sup>41</sup>

In Norway, it was not until after the Second World War that particular interest was shown in institutions. A period of extensive building was initiated after 1949 with legislation on the development of institutional services, to be financed with state funds. This process continued until 1976. Since then, the number of places in institutions has not increased. Towards the end of the 1960s, a period of institutional improvement began, concentrating on developing the services within these institutions. This period was characterised by an ambition to reduce the size of institutions, to introduce a greater degree of decentralization, to make the wards more home-like and to develop their educational and occupational facilities. These suggested improvements were a response to criticism of institutions and demands which originated in the Normalization Principle. The beginning of the 1990s has seen the start of a period of closure, furthered by a law which states that county specific services for persons with intellectual disability should be discontinued from 1992.

The dissolution of institutions has also become a reality in Finland where, from 1977, legislation pointed in the direction of community services, breaking a trend, which had existed since the 1940s, and which had led to an increased number of places in institutions. This trend has now reversed and institutional closure has begun.

In Iceland, early forms of services were institutional. Attitudes to these services changed in the mid 1970s when emphasis began to be placed on the importance of parents being able to keep their children at home while they were growing up and, as adults, being able to live in the local community, in housing with adequate support. Today, the process of dissolution has begun.

In Denmark, services for persons with intellectual disability have always been dominated by large institutions, though changes have taken place to reduce their size. Work has also begun on the dissolution of some of them, with some closures having already been achieved.

The academic literature in Scandinavia starts with a critique of institutional care at the beginning of the 1970s. In the late 1970s and the early 1980s, much attention was given to institutional reform, but since the mid-1980s, the emphasis has shifted to institutional replacement.

Thus, the overall picture is that the 1970s primarily involved projects aimed at the development of institutional services, whereas the 1980s was the decade in which their dissolution began. This process has affected everyone involved in services for persons with intellectual disability throughout these countries, and the dissolution of institutions is recognised as a task of fundamental socio-political importance in Scandinavian societies.

<sup>41</sup> Adapted from Mansell and Ericsson 1996



disabilities, families are also the most important resource for social inclusion. Families of people with disabilities provide the greatest proportion of community-based support to their disabled relatives. This leads not only to huge savings in the public budgets, but in many cases, prevents exclusion and segregation of disabled people.

Families are therefore an important resource that governments should seek to strengthen. Favourable conditions for families will help to support more children and young people with disabilities to live at home. The more families support the social inclusion of their children in society, the easier a move to more independent forms of living will be for their child in the future

Nevertheless, the families of severely disabled persons may not be able to provide the necessary support to enable their social inclusion. In some cases, this may lead to the disabled person being forced to stay at home,

into their adulthood, due to the lack of quality residential services. This can also lead to discrimination against the parents in terms of access to employment, poverty, the social exclusion of the whole family, as well as to huge human, social and financial costs.

### **1.7 The choice of service providers**

The choice of service providers should be linked to their capacity to ensure quality services and participation of the users or their representatives.

It has been demonstrated in many countries that NGO service providers, having a strong motivation to offer the best quality of life to the users, tend to offer a better cost – quality ratio than public bodies. This has led to a situation in the 15 member states of the old European Union, where the majority of all residential services for disabled people are provided by NGOs. This reflects a long phase of learning by governments and administrative bodies in many countries.

## The National Intellectual Disability Database in Ireland

The National Intellectual Disability Database was established in 1995. It is a set of information that outlines the specialised health services currently used or needed by people with intellectual disability. The database influences the strategic direction of these services through the provision of information on trends in service need, service use and wider societal changes that may impact on service developments. This service-planning tool answers four key questions:

- How many people with intellectual disability are receiving specialised health services?
- How many people with intellectual disability are waiting for such services?
- What services are they waiting for?
- At what point, in the next five years, do they need these services?

The National Intellectual Disability Database Committee prepares a comprehensive annual report based on the information held in the database at that time. The report provides a profile of the intellectually disabled population in terms of age, gender, level of disability, health status, etc. The report also monitors the current service provision to this population and assesses the future service requirements for the following five-year period.

In 2003, the number of people with intellectual disability requiring residential services was at its highest level since national recording began in 1995. There are now 1,776 individuals who require a residential service between 2004 and 2008. In contrast, demand for day services by 546 people is at its lowest level, suggesting that significant progress has been made in meeting the demand for day services.

## 1.8 Awareness raising and training

Awareness of community-based options for service provision and the benefits of these options must be raised by governments at all levels of society, administration and the decision-making process. It must be their objective to mainstream disability policy at all levels. Attitudes and awareness of different groups in society are absolutely essential for the success of community-based residential services.

Therefore, awareness-raising activities should concentrate on:

- Informing disabled people, their families and professionals about community-based services in their neighbourhoods.
- Promoting inclusion of disabled children in mainstream pre-school and school education.
- Creating awareness among policy-makers of the need to provide sufficient places in quality services.
- Developing capacity-building and training of local and regional administrations on disability planning and management.
- Training of disabled people, parents, other advocates and staff in quality control and management.
- Training of judges and lawyers in disability rights issues and establishment of a judicial system accessible to disabled people.

Awareness-raising activities must be developed to accompany the de-institutionalisation process since these are key within the overall process.

Training programs addressing lawyers, in conjunction with legal and professional bodies should be developed in order to ensure that disabled people have access to justice. Judges and lawyers would therefore be trained in disability rights issues, and would be prepared to apply the relevant legislation once it is in force.



## 1.9 Prosecute Human Rights Violations

It is not enough for governments to declare their support for the Human Rights of their citizens and to sign the appropriate international treaties and conventions. It is the duty of each national government to ensure that these rights are applied and enforced for all their citizens. Complaints about human rights abuses must be investigated thoroughly and in cases where serious human rights abuses have occurred, the alleged perpetrator(s) of such abuses must be prosecuted.

## 1.10 Allocate Structural Funds

The Structural Funds available for the new member states, for example in the framework of the European Social Fund, have proven to be an extremely important and effective means of improving the provision of quality services for disabled people. While the European Commission has a certain influence on the framework programming, it is mainly national governments that make decisions about the use of the Structural Funds.

Throughout the process of programming the use of Structural Funds at a national level, it is therefore important that national governments make a conscious and significant step towards allocating resources for the development of new community-based residential services. This programming should take the form of reserving dedicated budgets for the necessary infrastructure, training and running costs.

It is important that even at the first stage of programming, there is close consultation with disability organizations in order to avoid any developments which are contrary to the interests of the users of the services. Only in very exceptional circumstances, should ESF funds be invested in the improvement of existing institutions and their infrastructure, and even then only within the framework of a plan focusing on the provision of community-based services.

## 1.11 Fundraising and corporate social responsibility

In many European countries a significant amount of money for disability services is raised from the private sector through sponsorship of enterprises and public fundraising campaigns run by NGOs.

National governments should create the necessary legislative framework to allow disability NGOs to mobilize this financial resource. Furthermore, governments should appeal to national and international companies and enterprises operating within their borders to invest some of their gains in the social field. This is especially important in the new member states and accession countries where a sharp increase in economic capacity can be expected and where financial needs are greatest.

## 1.12 The commitment not to build new institutions and cooperation with the European Coalition for Community Living

A number of European national governments have already taken the important policy decision to support the transfer from institutional to community-based service provision. It will be important to create a European movement at government level, that uses examples of good practice for policies that support quality and inclusion in the provision of living facilities.

The project partners therefore call upon all European governments to sign up to the voluntary commitment to stop the building and financing of any new residential institutions that cannot ensure inclusion of people with disabilities in the community. Furthermore, governments are invited to cooperate fully with the Monitoring and Action Centre established by the European Coalition for Community Living that will ensure at a European level the implementation and follow-up of the recommendations of this project.



## 2. Local administration and policy

Administration at a local level represents direct contact and experience for people with disabilities. It is this level of decision-making that is therefore the most significant for changing policies and services for people with disabilities.

### 2.1 Local disability policy planning

It is most important that disability policy is planned systematically at local level. This planning must be undertaken in cooperation with disabled people, their families and their organizations. It must also include all relevant policy areas, i.e. disability policy must be mainstreamed in all local and regional policy.

Local administrations must base a sound planning on some fundamental principles:

- To enshrine respect for and promotion of the human rights for all their citizens
- The right of disabled people to inclusive quality services.
- The principle that a local authority must take responsibility for all disabled people originating from its territory. This includes those disabled people who have been displaced into large residential institutions in other regions in the past.
- The principle of the restriction of funding to quality services for the citizens.
- A realistic needs-assessment for services.

An excellent tool to facilitate local disability policy planning is the Agenda 22<sup>42</sup>. Local administrations should establish disability-planning councils involving disabled people, their families and their organizations as well as service-providers.

### 2.2 Changes in administrative and financing structures

All local authorities must put choice for disabled people and their relatives at the core of the provision of services. This will facilitate the process of change towards more person-centred services.

Defining clearer roles of the local agencies involved in service provision, would help both families and persons with a disability to be better informed about available services and entitlements. Procedures should be transparent and simple. The creation of a one-step information point at a local level would facilitate this communication.

Local governments should also support private community based residential initiatives as examples of models of good practice.

### 2.3 Implementation of quality assessment systems

When responsibility for the provision of residential services rests at the level of local or regional authorities, they also have a crucial role when establishing quality assessment tools. Regional authorities should make sure that financing is only provided to quality services that aim to inclusion of disabled people in society.

Nevertheless, it is vital that local authorities implement quality systems that are used by a number of other services within the same country in order to ensure comparability of service quality. Furthermore, training of users, advocates and external staff in carrying out quality control measures can best be organized as part of a network of services that all follow the same standards.

For local authorities in those countries where no compulsory systems of quality monitoring have yet been established by the government, it is therefore a good idea to start or join quality assurance circles along with other, neighbouring local authorities.

Furthermore, local authorities should consult with disability organizations at local, regional and national level in order to get advice on how best to install meaningful and person-oriented quality systems.

## 2.4 Awareness-raising and training

Awareness-raising is one of the most important means for local authorities to support community-based living for disabled people. As previously mentioned, it is often the negative attitudes of neighbours and local communities which can create problems for community-based services.

Local authorities have the opportunity to involve disabled people as valued members of the local community in all its activities. They often also have the opportunity to highlight the contributions of disabled people in the local press or to influence local reporting through targeted information for journalists.

It is also crucial that local authorities organise disability awareness training for all their employees in order to ensure that the needs of disabled people are taken into account in all relevant areas of local policy and administration.

## 2.5 The commitment not to build new institutions and cooperation with the European Coalition for Community Living

The partners of the project call upon all local administrative bodies to commit themselves to ending the building of new large residential institutions. They also encourage all local administrations to fully cooperate with the European Coalition for Community Living in order to promote community-based living for people with disabilities.

## 3 The European Union

The European Union and its institutions have important powers in the fight against discrimination (Article 13) and to pursue human rights, which are also relevant for disabled people in large residential institutions. Furthermore, it can lead through exchanges of good practice and policy development in its different programs.



There are, however, quite a few areas of policy-making which need to pay much closer attention to the issue of institutional service provision for people with disabilities. Within the frameworks of established EU policies and competencies, it is necessary to pay heed to the concerns of disabled people in a much more effective way, for example within the Open Method of Co-ordination in the fight against social exclusion.

Furthermore, the European Union must promote these processes to ensure full human rights and dignity for all its citizens. It must be seen to make a real effort to ensure the complete implementation of existing Human Rights instruments in all member and accession countries.

### **3.1 Commitment to stop the building of new large residential institutions**

Throughout the fight for more community-based service provision for disabled people, it is essential that the European Union supports a Europe-wide cessation of the establishment and construction of new residential institutions. This would give a Europe-wide impetus for such a commitment.

### **3.2 The policies against social exclusion and discrimination**

It must be clearly understood that institutional service provision leads to social exclusion, and is a form of discrimination. Segregating a whole section of European citizens from the daily life and the workings of society is discrimination and must be of major concern for European policy-makers.

In the field of non-discrimination policies, the European Union has the power to initiate policy development and exchanges between Member States on de-institutionalisation. The promotion of community-based service provision must have a high priority within the discussion on the new disability-specific Directive due to be announced by the Commissioner for Employment and Social Affairs,

Clearly, residential institutions are in danger of excluding people with disabilities from living their lives as part of society. The promotion of community-based services must be therefore form high priority within the framework of any policy against social exclusion. The European Commission and the member states must place this topic at the centre of the Open Method of Coordination process and any National Action Plan on social inclusion.

### **3.3 The implementation of Human Rights instruments**

There are various Human Rights instruments which can be used in the fight against social exclusion and degrading treatment in residential institutions, in particular

- the European Charter of Fundamental Rights
- the European Charter against Torture and Degrading Treatment
- the European Social Charter

The Project "Included in Society" calls upon the European Union to make fullest possible use of these instruments and to call upon member states to close immediately any institution in which serious and persistent degrading treatment or the violation of Human Rights is occurring.

Furthermore, The European Union should pay special attention to the human rights situation of disabled people in large residential institutions in their regular reports on the state of human rights in the European Union and beyond. In order to highlight the situation properly, it would be necessary to include a specific chapter on this topic in each relevant report.

### **3.4 The European Structural Funds**

The European Structural Funds are one of the most important instruments for the improvement and harmonization of living conditions in all countries of the European Union. It is absolutely necessary that these funds are used to establish community-based alternatives to residential institutions in the new member states.

### 3.5 The EU disability action plan

The multi annual action program that the European Union established following the European Year of People with Disabilities 2003, provides important possibilities for promoting community-based service provision. The anticipated annual report, in particular, must include dedicated chapters about the state of institutional care and the development of and community-based care.

In this respect, it is proposed that the Commission should support the existing partnership of the “Included in Society” project to establish the “European Coalition for Community Living”. The coalition will constantly monitor and report on the requirements for residential services for disabled persons and the development of community based care in Europe. With the unique collection of information about 2.500 institutions for disabled people in all European countries, the partners are well-positioned to provide this information as a regular input to the Commission reports.

### 3.6 Promotion of quality development systems

Within the programs of the 6th Framework Program on Research and Development, the European Commission should promote the establishment of clear models of user-oriented quality evaluation systems that should be promoted as obligatory in all member states.

European guidelines on quality assurance for residential services should also be created. These European guidelines must also address the ethical aspects of care for people with disabilities. They must reflect the fact that high quality is inextricably linked to the need to support and enable people with disabilities to express their own views about their lives and the services they receive.

### 3.7 The need of additional research

New member states often seem to experience problems with being unsure of how to proceed with de-institutionalisation, how to shift from the old system to a new one. There are already many successful solutions, and guidelines based on those examples might prove to be of great help for the governments of the new member states.

Furthermore, the research conducted in this project has demonstrated that little information exists at present about residential institutions and services in Europe. This should be addressed in the framework of future research by the European Union and must be taken into account in the work of EUROSTAT, the statistical office of the European Union.

## 4 NGOs and service providers

The most important roles of Disability organisations and family carer's groups lie in lobbying for adequate services as well as in the implementation and creation of the services where the people whom they represent live.

In all EU15 countries, it was the organisations of disabled people and their families who had pushed for the past 50 years for the establishment and/or improvement of residential services. Without their tireless work, very few of the modern disability services and policies we see today would have been developed. Some disability organisations have become self-help service-providers during this process in order to resolve the most pressing needs for their disability group.

### 4.1 Development of quality standards

For the development of adequate person-oriented systems of quality standards in the different European countries, it is essential that disability organizations, family carer's groups and service providers all actively

participate in the process. These quality systems must be based on the involvement of users, their families and their organizations in the monitoring process.

#### **4.2 Commitment to external quality control**

In the area of quality control and development of services, it is extremely important to lead by example. Therefore, all services provided by disability organisations, including those in countries where obligatory systems do not yet exist, should commit themselves to external quality control mechanisms.

Furthermore, disability organisations should demand the same voluntary commitment from all other service providers, including different levels of government, church-related services, and profit-oriented organisations. Disability organisations should make their commitment to quality control public and inform their

governments, as well as the European Coalition for Community Living about any service in their country that is not yet committed to external quality control measures.

#### **4.3 Conduct training of disabled people, policy-makers and staff**

Another central role for disability organisations and for some service providers is training and education: When we develop community-based alternatives in order to promote inclusion, we have to realise that this will take more than just the provision of suitable housing.

- Disabled people and their families must be informed about their rights and the ways in which they can exercise those rights. Furthermore, they should receive training in quality assurance, self-advocacy and policy in order to be equal partners with professionals.



- Policy-makers and administrations at all levels should receive disability awareness training delivered by disabled people themselves. This is clearly one of the most effective ways to improve public policy for disabled people.
- Staff members of organisations and services must receive constant professional training in order to maintain and improve their qualifications. It is also advisable to involve disabled people and their families in this training in order to stimulate a real dialogue between staff, service-users and their advocates.

Staff in current residential institutions should be informed about future changes in disability care. Those changes should be discussed with them as well as the new career opportunities that this all change will imply.

Specific educational programmes should be created for staff willing to work in community services. This would enhance the skills and knowledge of professionals and therefore lead to higher quality community-care settings.

#### **4.4 Fundraising and corporate social responsibility**

There are many good examples of highly successful fundraising for disability services by NGOs and service providers in throughout European countries. A significant amount of money is also raised through enterprise sponsorship.

Disability organisations at national, regional and local level should become actively engaged in these fundraising campaigns. It is very important, though, that disabled people are not portrayed as helpless objects of charity, but as valued citizens who need some support in specific areas.

#### **4.5 The commitment to stop the building of new large residential institutions**

As lobbying organisations and pressure groups, it is one of the most important tasks of

disability organisations and of service providers to make sure that the services provided by them follow established quality criteria.

Therefore the partners of the project “Included in Society” call upon all disability NGOs and service providers to publicly subscribe to and endorse the commitment to stop the building of new large residential institutions for disabled people.

#### **4.6 The European Coalition for Community Living**

The four advocacy organizations promoting the “Included in Society” project, Inclusion Europe, Autism Europe, Mental Health Europe and the Open Society Mental Health Initiative, are committed to follow-up the project with the establishment of a European Monitoring and Action Centre on community living.

The Coalition will be established by the four initial organizations who will then invite other interested organizations to join. They will set up a cooperation agreement for this purpose detailing the operational procedures of the Coalition. The agreement will ensure that the Coalition will always be controlled by organizations representing the interests of people with disabilities.

The Coalition will build on the existing data available for 2.500 institutions for disabled people in all European countries and update and extend this information. The present database provides a unique tool for creating and maintaining contact between a large number of institutions, for promoting exchange and providing them with information.

In addition to these functions, the European Coalition for Community Living will also be in charge of promoting the commitment to stop the building of new institutions as well as following and influencing European and national policy in areas concerning de-institutionalisation and the creation of community-based residential alternatives.



# Study on the legal and financial basis of residential services for disabled people in Europe

Conducted by the European Association of Service Providers for Persons with Disabilities (EASPD)

## 1 Introduction

The legal and financial frameworks under which residential services for people with disabilities are organised and regulated are very complex and very different once we start comparing countries. The historical, economic, social and political backgrounds of each country are some of the elements which determine the way the sector looks nowadays.

A purely comparative analysis of the different national, regional or local frameworks would be an impossible task for us to undertake in the space of year. Therefore, we chose to work with questionnaires distributed to different stakeholders. Using the framework drafted for collecting information, we wanted to see which kind of responsibility the state takes for the provision of residential services for people with disabilities. This part of our report will compare operations of benefits and services: “What they do, how they are paid for, and who runs the residential services?” Furthermore, we have compared outcomes. “Whether or not the different stakeholders benefit from the way the social system for residential services is organised, and more specifically, if the system promotes the shift towards a system of residential settings that enables people with disabilities to lead more independent lives with freedom of choice and equal opportunities”. We identified common issues in the different accounts of service providers. These issues were linked to the reports of how social services are organised in the different countries.

## 2 Organisation and funding of residential services

The following findings are based on the responses we received to two questionnaires which were directed to members of the EU Disability Advisory Committee and a number of service providers for people with disabilities.

### 2.1 Responsibilities in the field of service providing differ according to the country.

In Scandinavian countries, the responsibility for service-provision lies with locally based bodies. In Finland, the responsibility for service provision lies with the municipalities. Consequently, there are 450 different ways to provide services and as many ways to organise quality assurance and control. EASPD therefore believes that it would be better if this was more centrally coordinated. In Sweden, it is the state that is responsible for the legislation and general planning, but local authorities and county-councils decide on the quality and quantity of the practical measures undertaken to realise the objectives of the legislative framework. These local bodies also levy taxes themselves in order to finance their work.

This system is in contrast to both Eastern-European countries, where the central (national) authorities take care of the financing and organisation of residential settings and to Spain, Austria and Belgium, where mainly regional bodies (communities, provinces, etc.) are responsible for the financing and the organisation of residential settings.



## 2.2 Legislation that affects the transition to community based settings

At European level there are about 190 guidelines which could, in one way or another affect the disability sector in the member states (VAN BENNEKOM, I), key among these are:

- patient rights: free movement of persons and services;
- prescription of drugs and medicines;
- budget issues;
- recognition of diploma's and certificates;
- functioning of National Health Services;
- decree Decker-Kohl and Smits-Peerboom on rights and obligations of clients when they obtain services in another country of the Union.

Legislation at national or regional level which affects the disability sector:

- laws on residential institutions (admission to services, involuntary detention, use of restraints)
- laws on social assistance (cash & non-cash, rules on consolidating multiple cash benefits, decentralising provisions of cash benefits, targeting limited financial assistance)
- family law (foster care or adoption) to allow short term foster family care with non-relatives.
- laws on people with disabilities
- laws on client-involvement and participation
- laws on the role of NGO's
- laws on social services
- laws on social protection

Other laws that shape the social welfare context:

- laws on social insurances (health, pensions, family benefits, unemployment)
- laws on decentralisation of governments
- laws concerning employment and work (laws regarding responsibilities of professionals or employment for people with disabilities themselves, e.g. sheltered employment)

Local policies:

- Environmental issues;
- Construction guidelines and country planning...

Residential settings for people with disabilities are regulated through laws which are often

outdated and are not, in themselves, always directly related to the provision of residential services for people with disabilities.

In Spain, legislation dates mostly from the 1980's. Some new legislative measures from 2000 (Decree 176/2000) and Social & Health Programmes and Plans, for people with disabilities and mental health problems, attempt to maximise social integration and promote education and supported housing within the community.

According to the information received from authorities, legislation in Eastern European countries is still enshrined in the past, but new legislative measures are now being adopted. Since 2000, through an initiative of international agencies, the World Health Organisation (WHO), UNICEF and the Ministry of Labour and Social Policy, reform has been initiated in the Republic of Macedonia. A priority is the establishment of a broader choice in different types of community-based services for people with disabilities. In Bulgaria however, some recent legislative changes have been put into place to facilitate and promote the progress of de-institutionalisation; the Social Assistance Act and the National Strategy for Equal Opportunities for people with disabilities.

The situation in Scandinavian countries is different. In Norway, the need for a new legislation capable of promoting and sustaining community-based settings was recognised in the mid-1980's and this contributed to the adoption of an interim legislation: the De-institutionalisation Act. Sweden has new legislative measures dating from the 1990's, which sustain the abolition of the large residential facilities for people with disabilities.

In federal systems like Austria and Belgium, the situation differs again. In Austria, the main legislation controlling residential services for persons with disabilities dates from 1994, but new developments are following the principles of integration and normalisation in the form of community-based settings. In Belgium (Flanders) there are very specific legal arrangements, with a variety of decrees regulating the set-up of residential settings. However, the majority of this legislation was adopted in the 1970's.

### 2.3 Recent trends in the government policies

In some countries, such as Belgium, Austria and the UK, recent trends in government policies and legislative measures seem to favour the creation of and the shift towards alternatives to residential care. In Scandinavian countries and probably some other countries as well, the government policies actively favour the creation of community based settings, whilst in former communist countries (like Republic of Macedonia and Romania) the shift towards community-based settings is still completely unsupported by legislative measures.

In **Belgium (Flanders)**, most of the residential care is provided in services recognised by the Flemish Fund for Integration of People with Disabilities. Recent policy developments of this regional body are working towards the shift to more community-based settings.

Two different forms of living for people with disabilities can be distinguished in **Austria**: the care model – where the person is accommodated in a larger residential setting - and the community based model - which follows the international trend regarding this issue. Although community-based settings are still in the project phase, Austrian policy on this issue clearly adheres and follows the principles of a community-based support model.

In **UK (England and Wales, Scotland has a different legislative framework.)** the government is determined to provide a wider range of choices for persons with disabilities, especially when it concerns people who have higher support needs. These viewpoints were made explicit in the government White Paper: “Valuing People”, a unique document with key principles concerning people with learning disabilities. In July 2003 the Minister for the Community announced a cash injection of £ 87 million to be spent on creating extra care housing by 2006. Also, the government has provided an additional £ 170 million in 2003-2004 to enable more people to continue to live at home for a longer period. By 2006, £ 170 million are supposed to be available to support the training for social care staff.

**Scandinavian countries** are not only in favour of de-institutionalisation, but have already installed some systems of ‘de-institutionalised’ residential services for persons with disabilities and mental health problems, based both on legislation and government control. Large institutions were abolished by law in Sweden in 1997, a country which enjoys powerful backing from the popular movements representing people with disabilities. In Norway in the mid-1980’s a de-institutionalisation reform process started based on the ‘De-Institutionalisation Act’.

In the **former communist countries**, the situation is quite different. In Bulgaria, some recent changes at policy level are working towards the closure of different large residential settings and the opening of new services has started. The opening of ten new sheltered homes is planned for persons with intellectual disabilities. But the state has still a lot of work to do in adopting new regulations and adapting new regulations and standards to these. This is illustrated by the fact that these sheltered homes are the still the only residential services financed through the Law for Social Protection.

As for the Republic of Macedonia, legislation clearly favours the existence of large residential settings. Through the Law for Social Protection, the Ministry of Labour and Social Policy has a legal obligation to finance residential institutions for persons with intellectual disabilities. Still, some efforts towards the shift to community-based settings are being made. The Government has initiated a process of reform in 2000, with promotes the establishment of a wider range of choice of different types of community- based services for people with intellectual disabilities.

## 3 Barriers identified by service providers

### 3.1 Funding sources and regulations seem to remain fixed in the past.

A general finding is that in most countries, the legislation governing residential care is quite old. This might be one of the reasons why it no longer provides an adequate framework for the

organisations that need to respond to the current needs and wishes of people with disabilities and their families. Earlier, we have given an overview of the different laws and how recently they came in to force. The existence of recent legislation does not however, necessarily mean that current practice is already organised along new guidelines.

A lot of service providers report the following barriers regarding the legal measures that apply to them and to the disability sector:

- laws that are no longer in force still continue to guide practice
- news law try to introduce new systems but there is no t adequate funding available
- implementation is far behind legislation

Laws that regulate the residential support system in Belgium date from the '1970. Service providers consider it to be quite a rigid system, which does not allow much flexibility. Although no incentives to organise community-based settings exist in the legal framework, the authorities tend to turn a blind eye to service providers who choose to undertake new initiatives. However, this is not supported by additional budgets and there are no concrete plans from the government at this time, apart from a special workforce, to improve their policy in this regard.

In Bulgaria, a new legal framework has recently been introduced, which will form the foundations for further de-centralisation and de-institutionalisation. It consists of a Social Assistance Act and some regulations for its implementation, accompanied by other sub-delegate legislation. This includes criteria and standards governing social services for children and legislation on accessible environments. In this legislation there are no concrete incentives for alternative housing schemes. Providers and municipalities in Bulgaria may provide and organise all kinds of services, but the heavy financial conditions make it impossible for them to develop new forms of social services in the community. Most of the specialised services remain, however state-run. Furthermore, it seems that the so-called de-centralisation process of social services providing financial de-centralisation, has not been organised in

practice. This is a result of a lack of interest on the part of some providers and the small budgets available to them.

One of our respondents in the UK explains that there, there is quite a good legislative framework, but a lack of enforcement. The rights are talked about, but not enshrined and according to this service provider, this is due to the perceived lack of political importance and under investment. Despite the legal position and legislation, policy-makers have only focused on the cheapest solution and not on outcome based measures.

### **3.2 The old thinking...**

In terms of practical organisation we can reiterate the remark made above. Recognition and organisation of support services are still based on regulations which reflect the old medical approach and do not allow any flexibility. The set-up of alternative housing facilities is often based on the good will of a small number of people.

In the UK, where local authorities make decisions based on an assessment of need, some people are denied services because they do not reach this assessment threshold. This threshold might differ from one municipality from another. Thus, it appears that eligibility criteria are used to rule out many vulnerable people instead of making services accessible to them. At the same time, some service providers only attempt to fit people with special needs into the services they already offer. Commissioners continue to try to place people into existing types of services and support models. This myopic approach does not promote the development of more client-steered services. If the legislation was created and monitored by the different stakeholders involved, only those services, which are proven to have met the individual's needs in the way the person wants them to be met, would actually exist.

In Ireland, the government supports the development of community based living alternatives. Irish service providers have reported no financial bottlenecks in this respect. Instead, they are waiting for the introduction of a piece of disability legislation

which would entitle people with disabilities to an independent assessment of need as a minimum standard.

The financing of the disability sector in the Czech Republic is still based upon the number of beds. This has an inconsistent effect on the need to move towards more community-based services.

In Belgium, all services, which provide residential support, must adhere to the same standards, covering areas such as safety, overnight staffing, environmental issues, hygiene and quality regardless of the number of people who reside in the building. The costs that fulfilling these standards incurs, is only manageable if a service operates as part of a bigger whole. This makes it quite difficult for residential facilities to start working in a more de-centralised way. For example, a place of residence housing more than 3 people with a disability must meet 95% of the same demands as a large residential setting with 350 service-users.

The Organisation of financial mechanisms and working practices in service provision are based on institutionalised models. In France, for example, legislation, as well as finance, is very much centred around large residential settings.

The same applies in Finland where no concrete incentives exist to promote community-based services. Instead it is the actions of family carer's groups, and forward-thinking municipalities and influential professionals that initiate change and implement new methodologies. Some stakeholders in Finland are in favour of legislation to prohibit large residential settings, as it exists in Sweden and Norway. Furthermore, stakeholders find themselves in a situation where the decreasing financial support given to institutions has created greater co-operation between those involved in provision in search of new possibilities. In other countries, this approach has sometimes created a vicious circle of re-investment in existing solutions.

### **3.3 The slow-moving process towards more community-based settings.**

In some countries, for example Central and Eastern Europe, community-based services are only small and isolated programs. It will take a more global and holistic approach to make permanent and efficient changes. Furthermore there is limited public awareness of disability issues in these countries

In the Republic of Bulgaria, it will take some time to overcome the unfavourable traditions from the past, which saw accommodation in large residential settings as the single solution to the needs of persons with disabilities.

In the Netherlands and in Belgium, the governments have spent many years investing in the bricks and mortar of buildings in order to be able to support and care for large groups of disabled people. . For some government bodies, breaking this down feels like destroying capital. Alternative buildings and facilities to accommodate people with disabilities are not available and need to be constructed or adapted for the purpose. Factors relating to the building of new premises also slow down the process of de-institutionalisation.

In Austria, service providers are reporting only a slow adaptation of laws and practices reflecting the changing needs and circumstances of the disabled population. Authorities that are ill informed and disinterested are also finding the funding situation increasingly difficult due to the enormous cost rises in the social sector as a whole.

### **3.4 Person-centered funding**

The Person-centred budget was introduced in the Netherlands in 1995 in order to promote more independence and freedom for people with disabilities to arrange their own support and housing facilities.

Since 2000 a system of 'personal budgets' which allows people to organise their own care, has been in place in Belgium. This system will be extended to cover more types of service, but, at present, it is now only applicable to non-residential services. The

system is currently being expanded and restructured by a special task force funded by the Flemish Fund.

In Norway, money is allocated both directly to persons in need of housing and to the residential services. In Austria both services and individuals receive a budget to organize and manage support services or to buy care or extra support.

In the United Kingdom (England), there is a system of direct payment for persons with disabilities who use community care services. Disabled people receive this payment from local authorities. Local authorities are obliged, for the first time to offer people the choice of receiving a service or receiving a cash payment to purchase care that better suits their individual needs.

Service providers identified the following possible problems with individualised budgets:

- Position of the client as an employer
- The needs of the client group less visible to political and public scrutiny. The public and decision-makers are often unaware of what the client group would use the money for and what their needs are.

### **3.5 Co-operation between the different stakeholders**

There is often a discrepancy between the opinions and views of the different stakeholders like disabled people, parents, professionals and policy makers. Service providers believe that sometimes, the reluctance of parents to make the decision for their children to live in a community-based environment, as a result of their own fears, could lead to certain patterns of developments based on wrong assumptions. Parents are afraid that the community-based setting will be less safe. Often, they are scared of losing the support they may have obtained, sometimes after having been on a waiting list for a long time or having been forced to exert pressure on authorities

In some countries like the Czech Republic, a lot of services still work with medical personnel. There is a medical approach

towards disability and the care for people with disabilities. There is a lot of resistance from medical staff when they feel that their position is endangered because of the change in perspective inherent in a move towards more inclusive methodologies.

In Finland, people working in the disability sector complain that funding organisations do not take into account the changing values in the disability field. Resources continue to go to the more traditional settings, and not towards the development of innovative ideas and practices.

Austrian service providers complain about the disinterested attitude of policy-makers and the fact that they are not informed about recent developments in the disability field. This is also a complaint in other countries like Belgium where the government is not seen to be making the effort to give correct information about such developments to service providers.

### **3.6 Existence of waiting lists for residential services**

Long waiting lists for services are a problem that can be misinterpreted and this is often used as an excuse to invest in existing (large) residential facilities. Information, e.g. from the Czech Republic, has shown that the long waiting lists are misinterpreted as there being a big interest in the type of services for people with disabilities currently offered and this is used as an argument for the extension of the capacity of these large residential settings. This also has the effect of preventing the development, by the state, of alternative services like day opportunities or other less intensive forms of support like sheltered housing.

In the Netherlands, solutions for people on waiting-lists have been a high priority the last few years. These solutions, however, needed to be sought in alternatives to large residential services. Constructing buildings, like in the past, was no longer allowed. Nowadays, the idea of de-concentration is inherent in the policies relating to housing facilities in the Netherlands.

### **3.7 Restructuring the organisation of support services and providing incentives for service providers to set up community based services**

The philosophy of client-steered and needs-oriented support in the Netherlands has opened up many possibilities for new forms of support. Cross-sectoral co-operation, between day services, employment, training and housing and between services for different target groups, have resulted in more positive alternatives for people with special needs. In the Netherlands, it is possible to build facilities for people with disabilities independent from health and welfare arrangements. For example, through a co-operative agreement with a housing association for the buildings and houses their clients live in, support services no longer have to manage or organise housing facilities as this responsibility is taken over by mainstream associations. This is possible thanks to the improved flexibility of the legislation and it promotes the freedom of choice and inclusion of people with disabilities in the community.

In the Netherlands, it has also been suggested that mainstreaming can be promoted by making it possible for other people and organisations to build on land which belongs to a residential service in order to promote this reverse integration. However, because such facilities were often built in green, woody areas, there are often obstacles relating to environmental and country planning. In these cases, the rules and regulations of other policy areas, the municipality and the region, can hinder and slow the process.

Walloon service-providers complain about ineffective communication between authorities regarding certain issues. Subsidies for investment in residential facilities with more than 60 service users are no longer allowed, but there is no clear communication on the number of residents that are allowed in a new facility. Living with their parents, a person with a disability gets almost no state benefit except for a mobility allowance. This does not provide incentives for family carers and makes caring for a relative with a disability an arduous responsibility.

## **4 Promoting the transfer towards community based and inclusive solutions**

Based on the results of the research described above, EASPD has developed the following recommendations:

### **4.1 Provide real choices for people with disabilities**

Legislation needs to put the choice of the individual and their relatives at the heart of the planning process for every service. This way, only those services which have been proven to meet the needs of clients, would exist. Choice must be integrated as an essential concept in legislation in order to re-organise services for people with disabilities. This will facilitate and fuel the process of change towards more person-centred services.

### **4.2 Introduction of person-centred financing or personalised budgets**

Persons with disabilities and their families should have a choice in how they wish to receive support and in how they would like to spend or receive their benefits and budgets. The introduction of individual, personalised budgets is by far one of the most suggested solutions to guarantee the 'personalisation' of support packages. With the introduction of personalised budgets, support must be available for persons with disabilities to deal with employment issues and administration. Furthermore, to avoid people with disabilities and their needs becoming invisible to politicians and public scrutiny we should keep track on what these budgets are spend on. This will provide valuable information on the changing needs and requirements of the disabled population.

### **4.3 Simplify the legislative framework and/or clarify the roles and responsibilities**

The identification of clearer roles for organisational and financing bodies as well as clarity over the different ways to receive benefits and allowances would help parents and persons with a disability to be better informed about their entitlements. The creation of a body to facilitate



this communication, and to offer advice and information, like the National Disability Authority in Ireland, would be a big step towards a transparent process.

#### **4.4 Promote investment in new alternative service models and cut down on investment in old-fashioned residential services**

- **Avoid re-investment in existing large-scale solutions** in attempts to solve the problem of the large waiting lists. Thorough research on the current availability or non-availability of services needs to be done in order to develop a constructive long-term vision.
- **Equal conditions for state financing or financing from other authorities** for the different kinds of residential settings.
- **Support private community-based initiatives**, as examples of models of good practice, in a sustainable and structural way. This will help private bodies in their development of innovative service alternatives and offer more choice to the individuals with a disability.
- Subsidies for the construction of new buildings in the disability sector should be strictly regulated and only allowed for small-scale community based settings. This to **avoid newly constructed large buildings to accommodate persons with special needs**.
- **Invest in training for social care staff** focusing on providing support in mainstream and community-based settings.

**4.5 Make procedures transparent and simplify bureaucratic rules** for services that want to proceed towards de-centralised and small-scale units. Plans for re-structure or re-construction as part of a move towards community-based units should receive a more favourable treatment and procedural barriers should be limited to a minimum.

- **Adapt current legislative (quality) standards** for disability services (e.g. fire prevention, rules on hygiene and environmental issues etc) to allow small-scale settings to be established and run independently of larger structures and institutions whilst still meeting the required standards.

- **Offer individualised solutions instead of total packages of care.** This can be achieved through separation of different areas of support like residential support and support for daily living. Co-operation between different service providers, such as disability services and mainstream housing associations, should therefore be facilitated. An additional requirement of this approach would therefore be individually evaluated levels of support for each person.

#### **4.8 Overall management and financial plan**

The recommendations previously quoted, should form part of an overall action plan in which we can put visions and theoretical frameworks into practice. The setting up of an action plan with concrete short-term and long-term objectives and mid and long - term reviews, by every Member State should facilitate this process of change.

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