



Included *in* Society

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

Summary Version



Supported by the European Commission

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

www.community-living.info

This website includes the electronic version of the full text of the Final Publication of the project which is available in English, French, German, Hungarian, Polish and Romanian. This Summary Version is available in all EU/EEA and EFTA languages and can also be downloaded from the website of the project.

This report presents a summary of the results of the work carried out by the 'Included in Society' project. It would not have been possible without the dedicated work and support of the staff of the participating organisations. The project partners wish to express their sincere thanks to all persons in many countries who have contributed to the success of the project. 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.

The research on the situation of large residential institutions in Europe was co-ordinated and written by Jim Mansell, Julie Beadle-Brown and Sue Clegg.

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Disabled people have the right to be 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. All member states of the European Union are committed to the protection and promotion of human rights. The European Union's 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. However, only some member states have taken concrete steps to alter the policy of segregating disabled people from society, which, in itself, constitutes a major human rights violation.

Furthermore, there are numerous international and European laws that protect human rights and fundamental freedoms. They require individuals to be given 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. However, 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. The project "Included in Society" proposes five key principles for positive change in order to assist and underpin such work. These principles, which are based on existing human rights instruments, are as follows: respect, choice, participation, independence, as well as regional/local responsibility for disabled citizens.

The "Included in Society" project, co-financed by the European Commission, undertook the task of researching the present state of large residential institutions in Europe and to develop recommendations for the development of community-based residential services. The project was managed by **Inclusion Europe, Autism Europe, Mental Health Europe and the Open Society Mental Health Initiative**. 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 project work was also supported by the Association for Research and Training in Europe (ARFIE), the European Association of Service Providers for Persons with Disabilities (EASPD) and the Centre for Policy Studies (CPS) of the Central European University in Budapest.

Large residential institutions 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, of necessity, exploratory. Nevertheless, it provides a large amount of broadly comparable data and presents a relatively clear and consistent picture.

The empirical study on the number and characteristics of large residential institutions in 25 countries was carried out by all the project partners and their networks and 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 was 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) and showed 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 the 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 facility becomes relatively isolated from the wider community, unacceptable practices develop, 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 French institutions have half the number of residents sharing rooms than Polish institutions and a third to a quarter of the number of residents sharing rooms 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, where people live either in small group homes or in their own housing in the community but with adequate staff support for their needs, the institutional services considered in this study generally perform rather less well. For example, the assessment of the 'home-likeness' 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. 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 and 0.7, compared with 1.4 to 14.0 found in this study.

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 range from 2% (Romania) to 21% (France); equivalent results from community-based services are 43% (England) and 47% (Scotland). A study of residents in community-based services for people with mainly high support needs and intellectual disabilities in England, showed that 62% of people observed were engaged in meaningful daily activities compared to 5-27% of those living in the institutions in this study.

These findings are generally supported by other studies of community-based services in Britain, Sweden, Norway, North America and Australia.

Of course, community-based services also vary in their quality and this has been a source of concern to commentators. 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. 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-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. Rather, it is variation in staff performance that appears to be the critical factor in explaining differences in outcome.

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.

Policy and priority actions for quality residential services for disabled people

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.

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.

Protect and promote the rights of disabled people

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.

Mainstream disability policy at all levels

The “Included in Society” project 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. It is essential to involve disability organisations and family 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.

Establish and implement Action Plans

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 make clear reference to the situation of disabled people in large residential institutions.

Launch a European Awareness Campaign

There is very little public awareness about the serious adverse effects of institutionalisation on disabled people and their families among the responsible decision-makers in local authorities, organizations or policy. They are not they aware that public spending on 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.

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 confirm that large residential institutions are 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.

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.

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, even though NGOs provide equal or better services. National governments, therefore, must create laws and administrative conditions that link the financing of residential facilities to their capacity to respond to the individual needs of the users and to the quality of life they provide.

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

The creation of community-based residential alternatives will also require investments in infrastructure, training and human resources. 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 therefore 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.

3 Establish compulsory systems of quality monitoring and enforcement

Address disability issues in the framework of consumer protection policy

As yet, very few countries 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 the 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.

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

It has been demonstrated 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. The European Union should allow comparability across Europe by providing a typology of the standards for residential services.

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 of an outstanding quality should be supported and receive incentives.

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.

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 irrespective of the needs of the users, but as a global subsidy per person receiving the service. The project therefore calls upon all European governments to establish the principle that budgets are allocated on the basis of the needs of each individual user. The process of resource-allocation must be transparent and must be undertaken in co-operation with disabled people, their families and their representative organizations.

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, and is used to pay for whichever service the user wants to receive.

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.

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 both 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.

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 “Included in Society” project 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.

Contact details of the participating organisations



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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.”

This publication is a result of the “Included in Society” project which aims to analyze 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 Summary Version of the results of the project is available in all EU/EEA and accession country languages to facilitate national debates on residential services for disabled people. The complete results of the project are available in English, French, German, Hungarian, Polish and Romanian. All publications can be downloaded from the project website at

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