

Included in Society

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

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, communitybased 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.