



POSITION PAPER ON STRATEGIES FACILITATING THE DEVELOPMENT OF COMMUNITY BASED SETTINGS AND PERSON CENTRED SERVICES

EASPD

The European Association of Service providers for Persons with Disabilities (EASPD) represents over 8,000 social service provider organisations across Europe and across disability. The main objective of EASPD is to promote the equalisation of opportunities for people with disabilities through effective and high quality service systems. We believe in interdependence and partnership of user organisations, providers and authorities at all levels to tackle the challenges ahead. More information about the organization is available at www.easpd.eu.

BACKGROUND

The Convention on the Rights of Persons with Disabilities received its 20th ratification on 3 April 2008, triggering the entry into force of the Convention and its Optional Protocol 30 days later. This marks a major milestone in the effort to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms of persons with disabilities, and to promote respect for their inherent dignity.

Most European countries are in the process of ratifying the new UN Convention, which creates a unique opportunity and momentum for change. For service providers across Europe, the development of community based settings and person centred services as described in the UN Convention and other international scene-setting documents probably is one of the main challenges for the sector in the coming decade. The challenge is all about bringing the services to the people and not the people to the service.

With this position paper, EASPD wants to contribute to the implementation of the Convention and to finding a solution to the large segregating settings that still exist all over Europe. The paper is structured around 4 main parts: strategic recommendations, recommendations for the EU and the Council of Europe, recommendations for member states and general conclusions.

Although deinstitutionalisation and community based services are important themes across Europe, recent research clearly shows that especially in Eastern Europe, this issue needs to be addressed.

PART I: STRATEGIC RECOMMENDATIONS

Several European studies have confirmed that care for disabled people in large and segregating settings in Europe continues to fall short of acceptable standards in many cases. Most reports recommend a wider use of community-based and individualised services which offer better quality of life to people with disabilities, but are at the same time not necessarily more expensive.¹

EASPD proposes four types of actions to facilitate the development of community based and person centred services:

1. Political and legal action

- **A legal ban** on placement in large segregating settings is needed. Only cutting the supply line can ensure that no new persons with disabilities are housed in these settings.
- **Independent assessment** of the quality of services is absolutely needed: monitoring reports should go to the parliament and not to the ministries.
- Local responsibility for social and health service provision only works when well-monitored national **quality mechanisms** are installed.

2. Real stakeholder cooperation

- Only by **involving all relevant stakeholders** (people with disabilities, service providers, authorities), effective and efficient policies can be developed. Real stakeholder cooperation goes beyond listened to!
- **Work with actors able to deliver:** cooperation with non governmental organisations and committed local authorities is to be promoted.

3. Develop alternatives

- **Deinstitutionalisation is necessary but not sufficient.** Large segregating settings may not be closed if no alternatives are available!
- Therefore the **development of new alternatives** is crucial. A wide spectrum of services starting with family support and early intervention is needed. Regional and/or municipal multidisciplinary early intervention family support teams are part of the solution. All new alternatives should contribute to social inclusion and to social cohesion in societies.
- **Existing settings may not be changed into golden cages.** A new type of services is needed, not just a better version of the same!

4. Invest in people

- **Invest in people with disabilities:** A shift in paradigm has taken place from looking at people with disabilities as patients towards a more social and human rights model. People with disabilities need to be empowered and a stronger focus on their abilities instead of on their disabilities is needed.
 - Education in general and more specific the access to quality education plays a key role in this regard.
- **Invest in families:** Try to keep children at home and spend time and money on their relatives. The role of families in providing social services to people cannot be overestimated.
- **Invest in staff:** Training (and retraining) of staff (also at management level) is a must.
- **Invest in society:** Awareness raising at different levels (media, authorities, society,...) can be a helpful tool.

¹ EASPD contributed as a partner to the *Included in Society* project, financed by the European Commission, DG Employment and Social Affairs, in the framework of the European Year for Persons with Disabilities, 2003 and to the project *Deinstitutionalisation and community living – outcomes and costs*, financed by the European Commission, DG Employment, Social Affairs and Equal Opportunities, 2005.

CONCLUSIONS

Change needs to be built on correct legislative frameworks and on real stakeholder cooperation and needs to be underpinned by committed staff. Only then the development of sustainable new types of service provision is possible.

PART II: RECOMMENDATIONS FOR EU AND COUNCIL OF EUROPE

There is an important role to play for the different European bodies in facilitating the development of community based settings and person centred services:

1. The European Commission and European Parliament need to guarantee that none of the **structural funds** (especially the European Social Fund) is used to create new segregating settings. This can be done by including stronger guidance with regard to quality of social services in the guidelines for structural funds and other EC funding. A better monitoring of how the funds are spent in the member states is a must.
2. **Authorities at all levels will need to provide earmarked budgets**, specifically allocated to support member states to implement the changes needed in service provision for people with disabilities.
3. The Council of Europe and the European Union should facilitate the international **exchange of models of good practice** and learning across borders and cultures.
4. There is a role to play for the EU and the Council of Europe to further **develop a European Quality Principles Framework** for social and health services for persons with disabilities. Innovative work has already been done in the High Level Group on Disability of the European Commission and in the relevant bodies of the Council of Europe.
5. It is important that both EU and Council of Europe **promote a quick ratification of the UN Convention** among their member states. Effective monitoring of the implementation of the UN Convention is of course a must. Both the High Level Group on Disability of the European Commission and the CAHPAH of the Council of Europe play a key role.
 - a. It would be useful to bring together representatives of ministries of health, labour and social affairs in one international body to agree on a coordinated approach between the provision of social and health services and the assessment of their quality.
6. **Correct legal frameworks** are needed to be able to deliver quality services. The whole debate on the specificity of the sector and on the importance of social and health service provision in an ageing Europe is of utmost importance.
7. **The collection of comparable data** can provide the member states and stakeholders with needed information to facilitate the actual development of new types of services.
8. **A good understanding of the situation the sector is in in Eastern European Countries** is needed to be able to come up with tailor made solutions. Situations like pictured in the BBC Documentary 'Bulgaria's abandoned children' are below human dignity and need to be solved. Part of the solution is to not only blame Bulgarian authorities or to focus on Bulgaria only. Similar cases occur in other countries and a much broader answer is needed.

PART III: RECOMMENDATIONS FOR MEMBER STATES

Most competence in this policy area is with the member states. They are also responsible for the actual implementation of the UN Convention. Therefore we urge member states to ratify the UN Convention without any delay.

1. In order to facilitate the implementation of the UN Convention, **interministerial conferences** could be organised on a national or regional level. Such 'implementation conferences' should be organised with the involvement of different ministries, but also in close cooperation with people with disabilities, service provider networks and all other stakeholder involved. Only by involving all (relevant) ministries, real mainstreaming (one of the key concepts of the UN Convention) can be guaranteed.
2. **Decentralisation of competences to the regional and local level is sometimes risky.** Often budgets are lower at local level and budgetary issues are considered more important than providing high quality services. Monitoring of social service provision needs to be done on a more central basis.
3. A space needs to be reserved for social and health service provision to people with disabilities in **social municipal planning**.
4. **Authorities at all levels will need to provide earmarked budgets**, specifically allocated to support member states to implement the changes needed in service provision for people with disabilities.
5. **Schemes for direct funding** need to be developed. For example the concept of personalized budgets is one of the options to give people with disabilities more independence and to bring the service to the people instead of the other way around. By providing personalized budgets, people are kept away from institutions and they can enjoy services in the community.
6. **National assessments of the effectiveness** and the implementation of the legislation for people with disabilities in the different countries is a must.
7. **Better coordination is needed** between the different governmental bodies active in the field of disability. All should work together to assess the quality of the services provided by the existing settings.
8. **Training and support is needed** to set up new coordination and support bodies in the field of disability. An example could be to establish a governmental body offering methodological support to services for people with disabilities. This body should be made up of governmental providers, NGOs and other stakeholders.

PART IV: CONCLUSION

Stakeholder involvement in policy-making, planning and management leads to more realistic and effective policies and plans, as well as improves their implementation. The reasons for this are that greater information and broader experiences make it easier to develop and implement realistic policies and plans, new initiatives can be embedded into existing legitimate local institutions, there is less opposition and greater political support, local capacities will be developed and political interference minimized. Only through real stakeholder cooperation, service provision for people with disabilities can be improved and the implementation of the UN Convention can be guaranteed.

Stakeholder cooperation should lead to the development of an action plan facilitating the development of community based settings and person centred services. One of the key focuses in the action plan will need to be to earmark budgets allocated to this specific area.