



EASPD Position Paper on “the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015”

EASPD

The European Association of Service Providers for Persons with Disabilities (EASPD) represents more than 7,000 service provider organisations in 24 European countries. About 4 million professionals are employed directly through the delivery of services for people with disabilities and another 4 million staff are employed indirectly.

Goals

The main objective of EASPD is to promote the equalisation of opportunities for people with disabilities through effective and high quality service systems in Europe. This objective is achieved through:

- I. Services to members:* networking, exchange possibilities and information on EU policy and programmes;
- II. Policy-influencing:* offering service providers a voice in Europe;
- III. Research and Development* as a basis for innovation and improvement of service provision.

Values

EASPD, founded in 1996, and its members' services underpin the principles of the Standard Rules of United Nations on the Equalisation of Opportunities for Persons with Disabilities, the Treaty of Amsterdam, the EU Charter of Fundamental Rights or any other such instruments that respect the dignity of people with disabilities and promote inclusion, rights based effective participation and full citizenship of people with disabilities.

EASPD is committed to work in partnership with organisations representing people with disabilities, parents' organisations and authorities at all levels to further activities and goals of all parties concerned through a coordinated approach. Many of EASPD's member organisations are legally obliged - through their statutes - to involve people with disabilities and parents in their Management Boards. This enables to work in partnership and set common objectives for future development of services responsive to the needs of persons with disabilities.

THE COUNCIL OF EUROPE ACTION PLAN ON DISABILITY

In the last decade major political, economic, social and technological changes took place in Europe. These changes also had their impact on policymaking regarding people with disabilities. A fundamental shift took place from the medical model that stresses disability to a social and human rights model aimed at full citizenship; a paradigm shift from patient to citizen. For this reason, the Council of Europe Ministerial Conference on Disability (2003) set out a strategy to elaborate a Disability Action Plan, which focuses on human rights, full citizenship and the improvement of the quality of life of people with disabilities.ⁱ

EASPD welcomes the Disability Action Plan of the Council of Europe and fully underwrites the fundamental principles mentioned in the plan. In this document, EASPD wants to pay special attention to the accessibility, availability and affordability of services for persons with disabilities in Europe.

EASPD agrees that the role of the European Disability Forum is important and even crucial in the development and execution of the Disability Action Plan, but service providers for persons with disabilities may not be excluded from this discussion. Service providers in Europe supporting people with disabilities, represented by EASPD, have a vital part to play in effecting changes in the lives of people with disabilities in Europe and must therefore also be given the possibility to contribute to the debate. They could be of valuable help when the member states start to implement the Action Plan.

In this position paper, we will shortly present EASPD's comments on the different key action lines defined in the Action Plan.

KEY ACTION LINES

Participation in political and public life

EASPD agrees that participation in political and public life and democratic processes is essential for the development and maintenance of democratic societies.

Participation in cultural life

EASPD agrees that people with disabilities should be able to fully participate in cultural life. From our point of view, the focus should be on accessible info (easy-to-read information, adapted to the abilities of persons with intellectual disabilities) and on training of disabled persons in the use of this easy-to-read/understand documents.

Access to information and communication

Knowledge is an important step towards equality and the assertion of the rights of disabled people. Key is to promote an inclusive e-Europe with technology that integrates people with disabilities. An important step could be to gather comparative information on the accessibility of ICT and Internet for people with disabilities or staff and professionals working in the sector. Next to that, one has to take into account the availability of the ICT-tools.

We are concerned that progress in this important area may marginalise and isolate if no accompanying measures are taken into account. Particularly for people with a learning disability, access to and understanding of ICT (that is not adapted to their needs) is problematic. That is why it is very important to pay enough attention to high quality 'training of the trainers'.

Education

The Salamanca declaration (1994) clearly states that all youngsters, with and without disabilities have the right to adapted education in inclusive structures. 12 years later we see that a lot of children, especially those with more severe disabilities, still don't have the chance to enjoy this right to education. That is why we would add a bullet point to the objectives mentioned under this Action Line stressing the importance of comparable data on participation in educational schooling of severe disabled persons.

Good quality and an inclusive approach on the level of education are some of the most important conditions for people with disabilities to develop their potential and to become integrated in society. Knowledge is the basis for all development. Every child/person has the right to education, and this right must consequently include all disabled children/people. In the initial stages of all development schemes in the educational field the needs of persons with a disability must be taken into account. Member states should not forget the right to education for severe/multiple-disabled persons.

Life-long learning is highly important for disabled people. They may develop their skills more slowly than their peers, have greater support needs, and may need more opportunities extending through adulthood in basic literacy or numeracy, or to undertake vocational training. A specific focus on disabled people and on the promotion of learning through traditional non-traditional and non-institutional routes is needed.

Employment

A more coherent approach is necessary to guarantee the access of people with disabilities to real jobs. During the last decade there has been a paradigm-shift towards more person-centred services. Between sheltered employment at one side and employment on the open labour market at the other, people often forget that there is a continuum of combinations of both forms of employment and this reality should be stressed more.

Effective education, vocational training and programmes of supported employment can enable many disabled people who are currently economically inactive, to make a contribution to the Lisbon Agenda.

As EASPD, we would suggest adding to the introduction of this action line that at this time 76 % of the people with a severe disability in Europe are unemployed. In addition to this, governments don't pay enough attention to career possibilities for persons with a disability. Not only having a temporary occupation is important, but also the future perspectives of the job.

Adding an extra bullet point on 'access to supported employment services' in the specific actions of the member states could be an important surplus. The member states should also do a bigger effort to tackle the so-called 'benefit trap': people with disabilities should have the possibility to get in and out the open labour market without losing their allowance in a more flexible way (specific actions, 3.10). And when talking about employment of people with disabilities, one has to make sure to take all different aspects into account: in the action plan, for example, nothing is said about accessible transport for persons with disabilities to their workplace.

The built environment

No additional comments.

Transport

Accessible transport policies are a must for each person with a disability and EASPD subscribes the objectives and actions mentioned in this chapter. Nevertheless, we would

suggest adding a point on assistive animals. Very often persons with disabilities encounter problems when crossing the border with e.g. their 'guide dogs': transparent border policies are needed.

Community living

Today the service for persons with a disability is different from what we had 30-40 years ago. Services of today are developed through close cooperation and with the involvement of all stakeholders and of course with the direct participation of the person with a disability, his natural surrounding and his family. Services are now deeply rooted in society and will be organised in a tailor-made way. They will also address the needs of the individual person with a disability thanks to highly specialised knowledge and insight in disability related issues.

Services will cooperate with the mainstream and will support these mainstream services. The disability specific services will also make available their knowledge and their expertise to these mainstream actors.

The ultimate aim of the service provider sector is supporting and empowering people with a disability to live a full and active life in their community in a way that is the most appropriate for them. No matter if it concerns the participation at the community life as a partner, a family member, an employee, an employer, a colleague, friend or a consumer: the provider will empower and create awareness amongst other society members that the person with a disability can contribute and actively participate in his/her own way to the life of the community. Full participation in the community as a respected individual: that is the overall aim of the service provider in 2005.

To underpin, support and facilitate this process of individualised support services and community building, EASPD launched a 'Framework' to come to person centred services and community based services.

EASPD suggests adding an extra objective on the development of methods of networking to enable different types of providers to communicate and plan between all stakeholders and to add a point on the training and retraining of staff.

As an extra bullet point (3.11), EASPD would like the member states to evaluate their legislation if there are no rules that generate large settings or that enforce the development of community based settings.

Health care

Persons with disabilities make up about 11% of the population of Europe. As trends toward community life advance, they have become more visible and more likely to access generic health systems. Yet evidence suggests that there are striking disparities between the health of this group and that of the general population. As 'Health disparities' related to disability is today a leading topic in research, policy and practice, EASPD suggests to make more clear in the introduction that the health status of people with disabilities is significantly lower than with the rest of the population.

Mainstreaming is of great importance for people with disabilities and for the providers in the disability sector, but research shows that many individuals with disabilities have specific health needs. They may have more general and 'specific to their condition-related' physical and psychiatric health problems compared to individuals without a disability.

In the end, EASPD would like to add an extra 3.10 in the specific actions to be taken by the member states on the right to equal access to blood and organs for persons with disabilities. Soundings make clear that hospitals and other health services tend to exclude people with disabilities from their waiting lists for organs and blood.

Rehabilitation

EASPD agrees that rehabilitation of people with disabilities is a duty of the community, but we want to stress the importance of involvement of all stakeholders, service providers included.

Prevention of disabilities

No additional comments.

Social protection

On the European level the disability sector and the people with disabilities themselves might benefit from a number of quality principles for services for people with disabilities, going from support in employment, to education and to residential support. People with disabilities have the right to support! Principles could promote the person-centeredness of this support, and provide guidelines for new ways of service delivery: more accessible, available and affordable. The involvement of people with disabilities and their representatives in the set up is one of the most important conditions.

Legal protection

EASPD suggests adding the following to the specific actions of the member states (3.3): Assessing the impact on inclusion of new/coming legislation (Regulatory Impact Assessment).

Violence and abuse

EASPD could be of help for the Council of Europe in mapping the situation of people with disabilities in different types of services throughout Europe (Specific actions to be undertaken by the member states, 3.6) and in implementing the findings of the Hilary Brown report: 'Safeguarding adults and children with disabilities against abuse'.

Research and development

Comparative research would be useful on the provision and availability of services and on the availability of budgets and resources. For many years, there are a lot of problems regarding the number of people with disabilities who are on a waiting list for a certain kind of support. The waiting lists are too long, but this problem is not visible because of the lack of comparable data. It is important not to neglect this fact and to work towards feasible solutions that respect the problems of families and people in need of additional support. Especially in the search of workable solutions regarding the de-centralisation and deinstitutionalization of services, one must make sure not to deny support services to these groups.

More comparable data are also needed to identify the bottlenecks in sector related legislation preventing the development of Community Based settings (safety regulations, health and consumer protection regulations, staff and others).

Awareness rising

No additional comments.

CROSS CUTTING ASPECTS

People with disabilities in need of a high level of support

Policy makers still often forget the target group of persons with severe disabilities and high dependency needs. Actions to promote their involvement, citizenship and quality of life are often not accessible. On top of that, there are no comparable data available on this target group. Their high dependency on caregivers and professionals makes them especially vulnerable.

It is obvious how important a multi-stakeholder approach is for the promotion of the rights and dignity of people with disabilities. Families as well as professionals should be involved in order to come to clear agreements on attitudes and standards to ensure high quality support that is provided in a person centred way for them.

Ageing of people with disabilities

Increased longevity means that adults are expected to live longer lives and thus to encounter age-related risks for various health conditions. In other words: the longer people live, the more they become vulnerable and the more elderly people become disabled. From the table below, we learn that 72,5 % of the population of 75 years and older suffers from a functional limitation and 41 % even from a severe functional limitation. Along with the ageing population in Europe, the percentage of persons with a disability in Europe will boost.

Age	% Functional limitation	% Severe Functional limitation
15-24 years	6,3 %	2 %
35-44 years	13,4 %	3 %
55-64 years	34,2 %	12 %
65-69 years	45,4 %	18,5 %
70-74 years	55,3 %	22 %
75+ years	72,5 %	41 %

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Besides that, the process of ageing has specific effects upon disabled people over and above those experienced by non-disabled people. This matter will require urgent and explicit research if the full personal, social and economic potential of people with disabilities is to be realised in the near future. Such an outcome would help to create an open society for all ages.

Along with the fact that people with disabilities have an enhanced longevity, it also brings along other challenges like health concerns including Alzheimer's disease and other forms of dementia. Dealing with these age-related health problems often requires specialised knowledge. Mainstreaming on the one hand, but also co-operation of different levels of service providing agencies will need to ensure a high quality and respectful approach of these issues.

IMPLEMENTATION AND FOLLOW UP

Quality of services and training of staff

EASPD suggests adding to this paragraph that service providers are important stakeholders in this issue. They need to be consulted when themes related to quality and staff are discussed.

As a network of service providers for persons with disabilities, we also believe that the Council of Europe should develop a framework of quality principles. Once these principles are available, the Member States can further elaborate them to a well functioning quality system in Europe.

Involvement of representative disability organisations

The involvement of persons with disabilities and their representative disability organisations is self evident, but as already mentioned above, involvement of the service provision sector is as important. Service providers respond to the needs of people with disabilities and thus are needed around the discussion table.

CONCLUSION

Key words that EASPD want to put forward for the future actions of the Council of Europe regarding disability-related issues are: Affordability, Availability and Accessibility of mainstream and specific services in employment, education, housing, culture and leisure time. Greater accessibility of for example the built environment (including transport systems) is only one small aspect of making a society open for all. We will need to focus on all three of these concepts (3 A's) in relation to all areas of life in order to ensure that people with a disability can live their lives to the utmost of their abilities.

These 3 concepts could also be used as measurement tools to evaluate the current and past policies regarding disability issues. It would enable to map the bottlenecks in the required support this target groups needs to take their responsibilities and enjoy the rights like any other citizen of the Union.

Social service providers play a key role in these discussions. Although we agree that representatives of people with disabilities and their families are important consultation partners, we are convinced that the contributions of professional, service providing associations are as essential. Their role in raising awareness and as a bridge builder in an inclusive society cannot be underestimated. The position of the service providers enables them to reflect on a multitude of aspects such as:

- The cost price of the support services,
- The needs of staff and employers,
- The necessary changes in the social security and support structures in the member states,
- To give advice in order to support people with disabilities to reach the utmost of their abilities in every area of life.
- Transition and adaptability of services

For the years ahead, for the disability sector, it will be crucial to engage in partnerships by users, providers and authorities together to initiate the transition of the sector towards person centred and needs oriented services, tailored to the wishes of each person individually.

EASPD requests to be a direct contributor to the CoE's Action Plan to build genuine partnerships between the stakeholders already committed and involved together with EASPD.

ⁱ Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015.