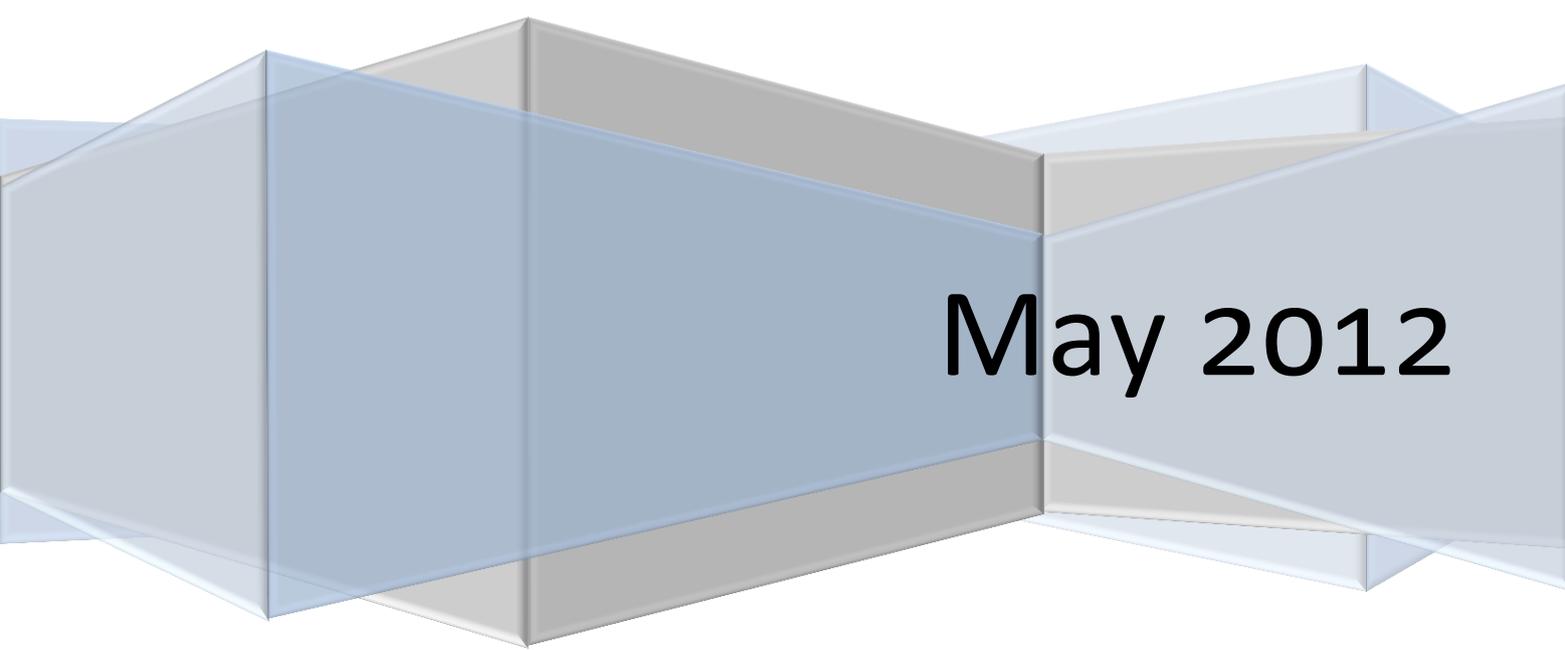




Support services: human rights enablers

EASPD position on the European Disability Strategy



May 2012

TABLE OF CONTENTS

Executive Summary, a service perspective on the european disability strategy	1
The UN Convention on Rights of Persons With Disabilities and the European Disability Strategy, Two different approaches to social and health services	1
EASPD POSITIONs ON THE EUROPEAN DISABILITY STRATEGY, EASPD standing committees comments on the eds	4
towards an effective implementation of the UNCRPD AND THE EDS, EASPD proposals to the European Commission	7
Innovation Agenda	7
Research Agenda.....	8
Implementation of the EDS in the EU bodies.....	8
Conclusions <i>EASPD reccomendations to the European Commission</i>	10
annex I: comparison between un convention and EDS	10

EXECUTIVE SUMMARY

A SERVICE PERSPECTIVE ON THE EUROPEAN DISABILITY STRATEGY

EASPD position paper starts with a **comparative analysis** of the European Convention on Rights of Persons with Disabilities (UNCRPD) and the European Disability Strategy (EDS). From this examination that when the role of social and health services for disabled persons is clearly stated in the UNCRPD, in the EDS services providers are not structurally involved in the strategy.

We believe that services providers have a crucial role in enabling human rights and that their contribution can play a key role in the implementation of the Strategy at a European level.

Therefore, we consulted our Standing Committees and Interest Groups that commented the Strategy and gave their advice about how further developing the service perspective of the EDS.

Based on the contribution of our members we launched some proposals on how EASPD could contribute to a successful implementation of the EDS and the UNCRPD.

Our proposal focuses on three key issues:

- **Innovation**, contributing with expertise on the best practices of individualised community based services
- **Research**, proposing methodologies for the monitoring of the implementation of the European Disability Strategy
- **Implementation of the EDS in European Commission bodies**, offering our know-how to enhance the inclusiveness of the European bodies.

THE UN CONVENTION ON RIGHTS OF PERSONS WITH DISABILITIES AND THE EUROPEAN DISABILITY STRATEGY

TWO DIFFERENT APPROACHES TO SOCIAL AND HEALTH SERVICES

Thanks to the Convention on Rights of Persons with Disabilities the perspective on service provision has moved from a paternalistic approach to a human right based approach: citizenship, participation, involvement and engagement are the key words for the future of services.

We welcomed the fact that the European Union concluded the UNCRPD in 2010, and that the ratification has been accompanied by the draft of the European Disability Strategy (EDS) 2010 – 2020 in order to help implementing the provisions of the Convention in practice, both at EU and national level.

During the meeting that EASPD had in November 2011 with Viviane Reding, Vice President of the European Commission, she

reaffirmed the importance of specialised service providers as strategic actors that, thanks to their know-how, are fundamental for the implementation of the UNCRPD and of the EDS. “EASPD inputs are needed”, Ms Reding said: she is looking forward to a productive and structural collaboration in the future. Moreover, together with the Disability Unit, EASPD will work on the development of a service perspective in the EDS.¹

This mandate has been one of the reasons for the present analysis that comes also from the awareness that service providers are fundamental in enhancing the quality of life of persons with disabilities. A common effort at all levels has to be done in order to foster innovation in the social services field, for high-quality community-based services, developed more and more on a holistic basis. All needs and choices of the person concerned, the beneficiary, the ageing person with increasing disabilities, must be at the centre of assessment and the resulting support services.

We tried to explore and analyze the two documents to find out where and when the role of services providers appears in both of them. The outcome of the comparison (Annex I) is clear: **the role of mainstream and specialized services is structurally integrated in the UN Convention**. Its general obligations include the duty for every State Party to promote training for staff working with disabled people to *better provide assistances and services guaranteed by the rights included in the Convention*. Services are thereby *de facto* identified as enablers of the rights declared in the Convention.

The Convention is seeking enjoyment of equal rights and opportunities by disabled persons. This is achieved on one hand **by developing accessible and inclusive mainstream services** and on the other hand **by providing specialized services based on individual needs**.

Whereas the European Disability Strategy and the UN Convention have broadly similar goals and objectives, we would like to highlight the fact that the role of service providers seems to be better taken into consideration in the UN Convention.

Social and health service providers seem to be hardly mentioned in the EDS but in very specific cases (independent living, social protection). We can find a reference to support, in a more implicit way, when the principle reasonable accommodation is mentioned (in the areas of Equality, Education and Training). **The main focus of the EDS is improving the accessibility of mainstream services, leaving apart the fact**

¹ Irene Bertana, EASPD, Report of the meeting with Vice-President Viviane Reding, <http://easpd.eu/Portals/easpd/Report%20of%20the%20meeting%20with%20Vice%20President%20Reding.pdf>

that individualized forms of support are, in many cases, preconditions for the enjoyment of rights. Specialised services are mentioned, but their role is not structurally integrated in the Strategy.

We believe that the role of service providers as enablers of rights should be recognised in the documents related to the European Disability Strategy, as for example in the next Plan to Implement the EDS 2015 – 2020. **Stating the role of service providers could open a space for cooperation that could give to service providers an important instrument of advocacy** at a national level. On the other hand **services can be already involved in the implementation of the EDS**, contributing with their expertise providing trainings, exchange of good practices and having a role in the implementation of the European platform Against Poverty.

EASPD has several Standing Committees and interest groups which are permanent working groups with a mandate from the board to advise, support and guide the board, the Secretary General and the headquarters. The Standing Committees on **Education, Employment, Enlargement**, our **Policy Impact Group** and our Interest Group on **Independent Living** provided us with inputs concerning the European Disability Strategy.

General considerations

Service providers and disabled people are interdependent and it won't be possible to reach success without a continuous dialogue between them. For the success of services it is important that the service structure and the quality of the services are achieved through the involvement of the users, on the basis of their needs and living conditions. European Acts and Strategies should take into account in a clearer way the role of mainstream and specialised services in guaranteeing the enjoyment of human rights for persons with disabilities.

Starting from this consideration, some general remarks in the European Disability Strategy regard the following subjects:

- **Service providers are not structurally integrated in the strategy as enablers of human rights**
- There is a **lack of references to intellectual/multiple/severe disability**: the entire strategy paper focuses mainly on the specific situation of persons with physical disabilities, giving a one-sided image
- **Training** of mainstream and specialised staff should be a priority of the strategy
- European Union should address the problem of **sustainability of funding** which undermines the quality of the services provided and in some cases also their availability
- **Quality of Life** should be the most important outcome measure; users should be asked for their personal feedback.

Accessibility

- The **role of social and health service providers** in helping persons with disabilities to overcome barriers should be stressed
- The concept of accessibility should have a **holistic approach** covering all aspects of life, and not only access to goods and services
- Regarding the main action foreseen, the **European Accessibility Act**, it should be **legally binding**, with **real force** and sanctions and a monitoring mechanism; furthermore, it must **apply to all people with disabilities**, including people with intellectual disabilities and people with high support needs
- **Persons with disabilities should be involved in testing accessibility**, using existing methods developed by service providers
- The need for a better implementation of accessibility in the mainstream sector: further efforts should be made to promote **Design for All**
- **Services** could play an **advisory role** towards governments and researchers on the development and use of **assistive technologies and PCT**.

Participation

- **Person centred planning** should be promoted in the service provision
- The will to optimise the use of Structural Funds and the Rural Development Fund to support the development of community-based services is welcome, in addition, more attention should be paid to the **support of the informal network** (informal carers and families) of a person, which is very often equally important.
- The moment of **transition** from institutional to community based care needs **special support**, e.g. through Personal Future Planning
- When talking about independent living, **supported parenting** is not mentioned in the strategy paper, but this should be included as a right for persons with disabilities
- **Persons with disabilities and their support providers should be structurally involved in the development of policy plans** about disability in general and in particular on independent living.

Equality

- The use of a medical terminology that displays disability as an individualized health problem should be avoided towards a more inclusive societal-based approach. As an important part of this process, there is an immediate need of **awareness-raising**, throughout society, of the rights of people with disabilities, promoting the recognition of skills, abilities, merits so as to combat certain mentalities, prejudices and discrimination that could lead to the use of such terminology
- **Self-advocacy** of persons with disabilities should be promoted.

Employment

- The screening of national/regional measures such as cooperatives and supported employment schemes foreseen by the Strategy is an acknowledgement of the role of service providers for persons with disabilities in the field of employment. However, **the role of service providers in the development and implementation of these support structures is not mentioned**
- The importance of adequate **sustainable funding** for supported employment services should be emphasized, as it is crucial for a successful long-term inclusion of persons with disabilities in the open labour market
- **Service providers** should play a bigger role in their efforts to establish **job services** and in providing **guidance and expertise** to public and private job services that support job searchers with disabilities
- A structural **cooperation between services** in the disability field, **employers** and **job services** should be established so that tailor made support and job coaching, when needed, is guaranteed. In the case of the implementation of **reasonable accommodation** in the workplace, this cooperation and **expertise** from services in the disability field is crucial
- The role of **sheltered workshops** services supporting integration in the labour market is not well understood. Open labour market is essential, but sheltered workshops can play an important role interacting with the open labour market in relation to **intra-job mobility** (training and qualification, outplacement, etc.). Workshops should receive adequate support to fulfill the role of **promoting transition towards the open labour market** and **integrating** persons with disabilities when they are no longer able to work in the open labour market (effective implementation of the “right to return”) or when it comes to **responding to the needs of persons with disabilities who cannot (yet) be integrated into the open labour market.**
- The **expertise of sheltered workshops** as employers should be made of better use in “**training**” employers in the open labour market, in particular with regard to management and training of staff members with disabilities.

Education and training

- **'Universal Designed' Educational programmes** or Learning Curricula at all school levels that include pupils with disabilities should be **created and used in the general education system**. Individualized support should be provided in case the universal design is not sufficient to respond to the needs of a student
- **Teachers should be trained to work with diversity** in their classroom, they should be able to work with parents and family when developing the Individual Education Plan (IEP) and communicate with families (on equal basis) on the evolution and progress of their pupils
- **Qualitative-based research** in the education field should be developed in order to identify the barriers preventing people with disabilities from exercising their rights. Indeed, qualitative-based research very often deepens the knowledge one has collected through quantitative research.

Social protection

- **Social service providers** and their representatives at European Level can play a key role in **implementing** the key actions of the **European Platform Against Poverty**
- **Sustainable funding** to service providers for persons with disability is a **prerequisite** to ensure the needed support to persons with disabilities.

Health

- **Research** is fundamental to support disability prevention and medical and psychosocial rehabilitation as well as to reduce the impact of the interaction between disability and other diseases (e.g. cancer).

EASPD PROPOSALS TO THE EUROPEAN COMMISSION

During 2011 all governance bodies of EASPD were invited to discuss the strategic orientation of the organisation. We live in a fast changing world and have to operate in rapidly shifting environments, as illustrated by the current economic and financial crisis.

EASPD decided, thus, to commit to enhance the quality of services, based on **Partnership** amongst stakeholders from the social and health sector, mainstream and specialised services. The overarching goal of services will remain **Participation**: support should be designed through a participative approach, facilitating inclusion in society. Services must respond to the changing needs and wishes of the individual. This is only possible through **Personalisation**, following the initiative and lead of the service user. In order to help achieve this, **Pre-conditions** for quality of services have to be in place, i.e. correct funding, stable and empowering legal frameworks and availability of skilled workers. The EASPD strategy 2011-2014 is built on **Partnership**, **Participation**, **Personalization** and **Pre-conditions** for quality.



Inspired by the UN Convention on the Rights of Persons with Disabilities, we hope to contribute to the development of a more accessible, social and caring Europe which respects and empowers people in need.

We would like to make three propositions of cooperation with the European Commission to contribute to the implementation of the European Disability Strategy on three different areas:

- **Innovation**, contributing with expertise on the best practices of individualised community based services
- **Research**, proposing methodologies for the monitoring of the implementation of the European Disability Strategy
- **Implementation of the EDS in European Commission bodies**, offering our know-how to enhance the inclusiveness of the European bodies.

INNOVATION AGENDA

High Quality specialized services enable the enjoyment of human rights, for this reason one of the three pillars of EASPD is innovation. In the last years EASPD members committed in enhancing the quality of services provided, developing expertise and know-how, through a number of European transnational projects.

We have concrete proposals about our contribution to the implementation of the EDS providing skills and best practices models to the European Commission, starting by the following areas:

- **Accessibility**: EASPD worked on **Person Centred Technology** (PCT) and its support to independence of people with disabilities and their carers, ImPaCT in Europe project developed an ethical code based upon a person centred approach. One of the findings of the project has been the lack of training for staff on PCT, EASPD can also provide trainings on the topic.

- **Participation:** programmes for **supported decision making** have been developed by many of our members; moreover, concerning **community based services** we can transfer at a European level our expertise on retraining of staff and budget reallocation.
- **Education:** EASPD and its members developed, through project financed by the LLP programme, innovative practices that could be further shared and disseminated. Moreover **inclusive education** has been a central issue for EASPD, working on *school for all* concept, developing strategies with regards to education system change and promotion of inclusive education.
- **Employment:** EASPD can contribute to the reaching of **Europe 2020 targets regarding employment**, with the analysis carried out about the effectiveness of policies on employment

Being an umbrella association representing 10.000 service providers for persons with disability, we are aware of the fact that many good practices exist in Europe. In this moment, where the need for services is getting higher, it would be important to promote and disseminate these good practices and raise awareness on the importance of quality of services to enhance the quality of life of their users.

To do so, we propose a series of actions to be inserted in an **agenda for change and innovation** that would include specialised services in the European Disability Strategy implementation work plan. It should focus on services and on how services facilitate the implementation of UNCRPD and EDS.

The agenda for change and innovation could work on:

- The exchange of models of good practices
- The acceleration of the change in care and support systems
- The promotion of innovation in delivery support
- The enhancement of the contribution of specialized services.

RESEARCH AGENDA

EASPD is willing to contribute to the implementation of the EDS General instruments with regard to statistics and data collection and monitoring. Improving the quality of services is crucial for the implementation of the UNCRPD and of the EDS, to do so a mapping exercise on the existing services is necessary.

EASPD would like to suggest the following **indicators** to the European Commission:

- **Spectrum of services:** mapping the existing types of services and their contribution to Quality of Life of persons with disability, identifying the proportion of community-based services compared to institutionalised and other types of services
- **Availability:** mapping the availability of services and their geographical and demographic coverage (rural/urban areas, etc.)
- **Funding systems for services:** Which institutional level is responsible for disability issues in EU countries (from local to national)? What type of resources is used to finance support systems (tax systems, incentive schemes for employers, etc.). How is funding channelled to services and disabled people? How are disabled people and service providers involved in decision-making processes concerning the funding of the disability sector?
- **Needs assessment:** What are the prevailing needs in terms of services for people with disabilities? Needs could be compared in different countries
- **Employment:** interaction between mainstream and specialised services (transfer rates from sheltered to supported employment), structures in charge (public/private)
- **Quality of services:** Assessment of existing systems is already in place. Why not using it at EU level?

- **Information systems on services for disabled people.**

IMPLEMENTATION OF THE EDS IN THE EU BODIES

European institutions should lead by example and make sure the needed instruments are available to meet the required outcomes.

EASPD can provide its expertise to launch the following services to further promote the inclusion of EU bodies:

- **Supported Employment Agency** for EU bodies to promote employment of people with disabilities (and other people in need) within EU bodies
- **Accessibility contact points** to encourage EU bodies to fully implement the “design for all” concept in the built environment, in communication systems (web sites, documents, leaflets...) and actions
- **Agency for special education needs** for children of the EU-civil servants.

CONCLUSIONS

EASPD RECOMMENDATIONS TO THE EUROPEAN COMMISSION

From our experience and from the UNCRPD analysis, it clearly emerges that services providers are enablers of rights. Their involvement, together with the one of persons with disability is fundamental to implement the UNCRPD and the ESD.

EASPD has expertise and tools to give to policy makers thanks to the everyday work carried by its members. Our network is willing to work to innovate the service provision and to improve the quality of services and the quality of life of persons with disability.

Therefore, we ask to the European Commission to include a service perspective in the European Disability Strategy, starting from the future plan to implement the European Disability Strategy 2010-2020, List of Actions 2010-2015.

Moreover, we think that the contribution of the service providers for persons with disability can make a difference now in the implementation of the Strategy.

For this reason we ask to the European Commission to cooperate with us on this three areas:

- **Innovation Agenda**, for a social innovation in service provision
- **Research Agenda**, to have a picture of the existing services for persons with disability and of their coherence with the principles stated by the UNCRPD
- **Implementation of the EDS in European Commission bodies**, enabling EU institution to lead by example about inclusion and accessibility

ANNEX I: COMPARISON BETWEEN UN CONVENTION AND EDS

UN Convention	European Disability Strategy / Initial plan to implement the European Disability Strategy 2010-2020 - List of Actions 2010-2015
TRAINING OF STAFF	

<p>According to Article 4 of the UN Convention, about general obligations, State Parties undertake:</p> <p><i>To promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights.</i></p>	<p>Training of staff is mentioned in the ambit of the key action Participation: concerning the transition from institutional to community-based care <i>Structural Funds and the Rural Development Fund will be used for training human resources and adapting social infrastructure.</i></p> <p>Training in other occasion is directed to mainstream workers, to improve their capacity to work with persons with disability:</p> <ul style="list-style-type: none"> - Area Participation, <i>Promote the dissemination of good practices regarding training of public officials on receiving and informing persons with disabilities;</i> - Key action Education and Training, in order to achieve inclusive education <i>adequate training and support for professionals working at all levels of education will be provided</i> And <i>Promote training of health professionals on disability matters through the ESF</i>
EQUALITY AND NON-DISCRIMINATION	
<p>According to Article 5 of the UN Convention:</p> <p><i>In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided;</i></p> <p>Where reasonable accommodation means <i>necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;</i></p>	<p>Area for action equality:</p> <ul style="list-style-type: none"> - Key action: <i>Provide guidance on reasonable accommodation for people with disabilities addressing employers and service providers</i>
ACCESSIBILITY	
<p>According to Article 9, State Parties shall take appropriate measures:</p> <p><i>(e) To provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;</i></p> <p><i>(f) To promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;</i></p>	<p>Neither in the EDS, nor in The Initial plan to implement the European Disability Strategy there is reference to social services as support to accessibility.</p>
INDEPENDENT LIVING	
<p>According to Article 19 of the UN Convention, State Parties will ensure that:</p> <p><i>(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or</i></p>	<p>Under the area Participation the Commission commits to promote the transition from institutional to community-based care by: using Structural Funds and the Rural Development Fund to support the development of community-based services</p> <p>one of the key actions is:</p>

<p>segregation from the community;</p> <p>(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.</p>	<ul style="list-style-type: none"> - Develop and disseminate a quality framework for community-based services that is inclusive of person with disabilities building on the quality framework for Social services of general interest
EDUCATION	
<p>According to Article 24 of the UN Convention, State Parties in realizing the right to inclusive education shall insure that:</p> <p>(d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;</p> <p>(e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.</p> <p>And</p> <p>4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.</p>	<p>The objective of the area for action Training and Education is to ensure that people with disabilities receive the support required, within the general education system, to facilitate their education, and that effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.</p> <p>In between the key actions:</p> <ul style="list-style-type: none"> - Disseminate research, information, and guidance materials on the application of the reasonable accommodation principle in education and training;
HABILITATION AND REHABILITATION	
<p>According to Article 26 of the UN Convention, State Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:</p> <p>(a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;</p> <p>2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.</p> <p>3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.</p>	<p>Also in the case of health and rehabilitation, the focus is on improving the accessibility of mainstream health services:</p> <ul style="list-style-type: none"> - Promote training of health professionals on disability matters through the ESF
WORK AND EMPLOYMENT	
<p>According to Article 27 of the Convention, State Parties will assure the right to work undertaking to:</p> <p>(e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;</p> <p>(i) Ensure that reasonable accommodation is provided to</p>	<p>One of the key actions of the area Employment is:</p> <p><i>Identify and promote effective support structures</i></p> <ul style="list-style-type: none"> – Screening of national/Regional measures (e.g. quotas, social partnerships, cooperatives, supported employment, transport) – Analysis of the employment effects of informal and family

<p>persons with disabilities in the workplace;</p> <p><i>(k) Promote vocational and professional rehabilitation.</i></p>	<p>care, with particular attention to gender issues</p>
<p>ADEQUATE STANDARD OF LIVING AND SOCIAL PROTECTION</p>	
<p>According to Article 28, States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families and promote the realization of this right including measures:</p> <p><i>(a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;</i></p>	<p>The Specific objective of the area Social Protection is to ensure decent living conditions for people with disabilities through access to social protection systems and poverty reduction programmes, disability-related assistance, public housing programmes, and retirement and benefits programmes; namely optimising the use of the European Platform against Poverty and the ESF.</p>
<p>PARTICIPATION IN CULTURAL LIFE, RECREATION, LEISURE AND SPORT</p>	
<p>According to Article 30 of the UN Convention, with a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, State parties shall take appropriate measures:</p> <p><i>(b) To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;</i></p>	<p>Under the area Participation one the key action is:</p> <ul style="list-style-type: none"> - <i>Promote the participation of people with disabilities in European sport events as well as the organisation of disability-specific events including Special Olympics</i>
<p>INTERNATIONAL COOPERATION</p>	
<p>According to Article 32 of the UN Convention, States Parties recognize the importance of international cooperation and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:</p> <p><i>(b) Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;</i></p>	<p>One of the key actions of the area External Action is:</p> <ul style="list-style-type: none"> - <i>Support where appropriate the institutional strengthening of Disabled Peoples' Organisations in partner countries and organisations dealing with disability and development</i>
<p>NATIONAL IMPLEMENTATION AND MONITORING</p>	
<p>According to Article 33 of the UN Convention Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process ;</p>	<p>Independent mechanisms are foreseen in order to monitor the implementation of both the EU Disability Strategy 2010-2020 and the UNCRPD.</p>