



## **It is your Business:**

# **An Analysis paper on the implications of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and its Optional Protocol for Service Providers**

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## **1. Introduction**

This paper reviews the recently ratified UNCRPD from the perspective of service providers operating within the EU.

It explores the potential impact of the convention in general and the role of providers of services particularly in the domains of health, education, long term care, independent living, employment and rehabilitation.

It addresses the Convention from a number of perspectives including:

- The challenges and responsibilities for service providers inherent in the implementation of key articles of the Convention,
- The range of services that are specified within the Treaty,
- The opportunities for service providers which arise from the Convention in national and international terms,
- The actions that service providers can take to ensure the effective implementation of the Convention.

Section 1 of this paper provides a general introduction to the Convention and its Optional Protocol. This is supported by an Annex which provides the exact wording of some of the key articles and the current status of the ratification process. Section 2 aims to analyse the content of these articles and the Convention in general from a service provider perspective.

### **Section 1 – A description of the UNCRPD and its Operational Protocol**

The UNCRPD is a legally binding international Human Rights treaty. Those countries that ratify this Convention commit themselves internationally to implementing the provisions of this legal text. Disabled people are now addressed as persons with rights and a full role to play in society and not only as patients needing a cure.

Together with the Convention, an Optional Protocol has been adopted to be ratified separately. The optional protocol enables each citizen to submit complaints to the Committee of independent experts.

The UN Convention provides governments, the disability sector, industry and service providers with a clear framework for ensuring people with disability are treated fairly and equitably in all aspects of life.

The Convention and its Optional Protocol which entered into force on 3 May 2008 represents a great achievement in the effort to ensure equal enjoyment of all human rights and fundamental freedoms of persons with disabilities. It was negotiated during eight sessions of an Ad Hoc Committee of the General Assembly from 2002 to 2006, making it the fastest negotiated human rights treaty. The Convention is considered to be a "paradigm shift" in attitudes and approaches to persons with disabilities. Disabled people are now addressed formally as persons with rights and a full role to play in society.

The purpose of the convention is to promote, protect and ensure the full and equal enjoyment of all human rights by persons with disabilities. It covers a number of key areas such as accessibility, personal mobility, health, education, employment, habilitation and rehabilitation, participation in political life, and equality and non-discrimination. The Convention marks a shift in thinking about disability from a social welfare approach, to a human rights agenda, which acknowledges that societal barriers and prejudices are themselves disabling.

Critically, the convention recognises that the right to access services is as essential as civil, political, social and cultural rights for people with disabilities. A range of services are either explicitly referenced in the Treaty or are strongly implied by its wording. This is a fundamental departure from many previous approaches to protecting the rights of people with disabilities and is far more proactive than some non-discrimination and equality measures that are in operation across the world.

The onus is on those who support the approach adopted in the Convention to ensure that the full impact of the Convention is implemented in all Member States that ratify the Convention. This includes representative organisations of persons with disabilities and service providers alike.

## **I. The Way the Convention Works**

The Convention has established two formal bodies in order to monitor the implementation process.

- A Committee on the Rights of Persons with Disabilities: The Committee is a body of independent experts with the task of reviewing States' implementation of the Convention. The Committee will have a membership of 18 experts, who will serve for four years in an independent and autonomous way. States Parties will provide a report to the Committee after two years of signing the Convention and subsequently every four years, giving a comprehensive explanation on the progress made towards implementation of the Convention.
- A Conference of States Parties meets every two years (or upon decision by the Conference) in order to consider any matter with regard to the implementation of the Convention.

The signature of the treaty is the first step of the adhesion process to the Convention. States and regional integration organizations (RIO) may sign the Convention or Optional Protocol at any time. The signature represents a clear act that shows the intention of the State to take steps to be bound by the treaty at a later date. Signing also creates an obligation, in the period between the signature and the ratification, to refrain from acts that would defeat the object and purpose of the treaty.

The ratification is the next phase in becoming a party to the Convention or Optional Protocol. The ratification is a concrete action taken by States which commit themselves to

undertake legal rights and obligations contained in the Convention or the Optional Protocol.<sup>1</sup>

The accession is a further act a State or regional integration organization may take to express its consent to be bound by the Convention or Optional Protocol. Accession has the same legal effect as ratification; however, unlike ratification, which must be preceded by signing to create binding legal obligations under international law, accession requires only one step – depositing the instrument of accession.

It is important for service providers to keep abreast of this process and to actively engage in lobbying to ensure that Member States fully endorse the Convention not only because it underpins the rights of persons with disabilities but also because the Convention points the way for the future development of services and the principles upon which these services must be based.

When considering the role that service providers can play in the implementation of the Convention, it is important to keep in mind that the primary focus of the Convention is on State Parties rather than civil society. As such it is the Government of the day which must ratify and implement the Treaty. Of necessity the way in which service providers must act in relation to the Convention is to proactively promote its full implementation in partnership with representative organisation of people with disabilities in their own jurisdiction.

The Convention places a requirement on Member States who have committed to implementing the Convention to:

1. Establish focal points in Government with responsibility for the implementation of the Convention,
2. Put in place a coordination mechanism,
3. Construct a framework for monitoring the implementation of the Convention,
4. Create independent mechanisms to review the performance of the Member State.
5. Report on progress on the implementation within two years of ratifying the Treaty and every four years subsequently

Internationally an International Committee for the Rights of People with Disabilities consisting of 12 – 18 approved independent individuals will monitor the national reports. In the case where the Optional Protocol has been signed the Committee will review the complaints of individuals or groups in the event that national procedures have failed to resolve the issues.

This paper concentrates on a number of articles for which the contribution of services is critical.

These are:

- Art 19 Living Independently
- Art. 24 Education
- Art. 25 Health
- Art. 26 Habilitation and Rehabilitation
- Art. 27 Work and Employment
- Art. 28 Adequate standard of living and social protection

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<sup>1</sup> Regional integration organizations express their consent to be bound by the Convention or Optional Protocol through “formal confirmation” – an act which has the same effect as ratification.

The main thrust of these articles is described below and the full text is provided in Annex 1 to this document.

#### Article 19 Living Independently

This article sets out one of the overarching intentions of the Convention with respect to adults with disabilities i.e. persons with disabilities have the right to live independently in the community and to exercise choices in the same way as anybody else. To support this right States are required to put in place whatever measures are required to ensure full inclusion and participation in the community and in particular to provide a guarantee to people that they can select where, how and with whom they live and are free from coercion in this regard. To underpin this right States must make sure that persons have access not only to community services that are available to the general population but also to a range of targeted and customised in-home, residential and community services including personal assistance services.

#### Article 24 Education

States are to ensure equal access to primary and secondary education, vocational training, adult education and lifelong learning. Education is to employ the appropriate materials, techniques and forms of communication. Pupils with support needs are to receive support measures, and pupils who are blind, deaf and deaf-blind are to receive their education in the most appropriate modes of communication from teachers who are fluent in sign language and Braille. Education of persons with disabilities must foster their participation in society, their sense of dignity and self worth and the development of their personality, abilities and creativity.

#### Article 25 Health

Persons with disabilities have the right to the highest attainable standard of health without discrimination on the basis of disability. They are to receive the same range, quality and standard of free or affordable health services and not to be discriminated against in the provision of health insurance.

#### Article 26 Habilitation and Rehabilitation

This article commits the countries to provide comprehensive habilitation of persons with disability from birth and rehabilitation services in the areas of health, employment and education for those individuals with acquired disability, with the overall aim to enable persons with disabilities to attain maximum independence and ability.

#### Article 27 Work and Employment

To ensure equal rights to work by persons with disabilities, countries are to:

- Prohibit discrimination in job-related matters
- Promote self-employment
- Entrepreneurship and starting one's own business
- Employ persons with disabilities in the public sector
- Promote their employment in the private sector
- Ensure that they are provided with reasonable accommodation at work.

## Article 28 Adequate standard of living and social protection

States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

The focus on these articles is not intended to de-emphasise the importance of other articles in the Convention that have important implications for service providers but to elaborate the wide range of services which are required in order that national authorities meet their commitments under the Convention. Section 2 provides an analysis of the responsibilities accruing to service providers as a result of the Convention, the services that are required to support its implementation and the opportunities which the Convention can create with specific reference to Articles 24-28.

## **Section 2 – A Service Provider Perspective on the UNCRPD**

From the perspective of service providers and individuals with disabilities the UN Convention will only impact indirectly through the mechanisms that are put in place by a particular Member State to implement the Treaty. It is also the case that should a State Authority choose to de-emphasise or ignore a specific element of the Convention, the main recourse is through the International Committee for the Rights of People with Disabilities. If the Member State in question has not signed the Optional Protocol, which would allow an individual case to be brought against the State Party, the main channel for bringing such an omission or flawed strategy to the attention of the International Committee is through the reporting procedure which requires signatories of the Convention to report within two years of signing and every four years subsequently.

It is important that this context is kept in mind when interpreting the text of the Convention either from the perspective of an individual citizen with a disability who is seeking to actualise their human rights or a provider of a service specified with the text. The implementation process within a jurisdiction can not stop at the point where the UN Convention has been ratified but must continue not only in terms of monitoring and reporting but also in terms of progressive realisation. Central to this must be the active involvement of civil society, including service providers and organisations of people with disabilities, in the production of the initial report. Based on this report and the gaps and areas for improvement identified within it, the improvement agenda can be set for the subsequent four years. If this watershed is missed, it is likely that the agenda for change will have been set and major adaptations will be difficult to promote.

There is no compunction on service providers to actively engage with the Convention process. It does not place any specific concrete roles or responsibilities on individual entities with a jurisdiction. Thus a provider organisation could remain passive in relation to the implementation process and leave it up to representative organisations. In so doing the primary risk that faces such an organisation is that it will be unprepared to respond to the changing requirements for services arising from the implementation of the Convention. However, more broadly than this, the organisation will almost certainly miss out on opportunities to engage in active service development and innovation arising from the services oriented approach adopted by the Treaty.

Another approach would be to monitor the implementation process to ensure that the organisation remains up to date with evolving trends and standards emanating from the Convention without investing any effort in actively influencing the way in which the Convention is interpreted, implemented and monitored. While averting the risks of non-

compliance with new standards, this approach does not provide a platform for active service development.

Finally, service providers could actively engage in lobbying the statutory authorities to ensure that the full implications of the Treaty from a services perspective are included in the initial report to the International Committee and in the subsequent national improvement plan.

This is the approach adopted in this paper. It is predicated on two basic assumptions. The first of these is that it is in the best interests of people with disabilities and broader civil society that service providers become actively involved in developing the national disability strategy to implement the UN Convention. The second is that it is in the best interest of service providers to proactively engage with internalising the principles and requirements of the Treaty into their own organisations, lobbying and promoting its full implementation both nationally and internationally and ensuring that their strategic planning processes fully incorporate the implications of the Convention for services.

## **I. Challenges and Responsibilities**

### **Making sure that Member States sign the Optional Protocol**

The virtue of having a Member State adopt the optional protocol can not be underestimated. In the absence of the Protocol, there little or no option available to an individual with a disability, who believes that his or her rights are being denied under the Treaty, other than to use national mechanisms. In the event that these do not provide an acceptable outcome for the person the most that can be expected is that the specific circumstances of the case are recorded and reported in the subsequent report to the International Committee. This could be four years later when the next report is required and many more years after that before the issues are put right.

The value of the Optional Protocol is that it provides another level of redress to the person who has tried all the appropriate national channels and has not found satisfaction. It creates a dynamic structure through which systemic issues can be addressed between reporting periods. It also makes the Treaty more 'real' for people with disabilities and can make it something that they can refer to in their day to day lives.

In some Member States it may well be too late to convince policy makers and statutory administrators to sign up to the Optional Protocol but it is certainly an aspiration that service providers should work towards in partnership with representative organisations of people with disabilities.

### **Influencing the implementation agenda**

The complexity and scope of the UN Convention will require Member States to manage efforts and resources by setting short and medium term priorities and emphasising certain aspects of the Treaty. These choices will be made by policy makers and statutory administrators who have a track record in many Member States of re-interpreting existing measures and approaches within the frame of new legislative requirements rather than embarking on major change and innovation. This political conservatism must be counterbalanced by a strong disability platform representing all aspects of civil society including people with disabilities and service providers that is supporting a mutually agreed agenda for implementation that balances equality and non-discrimination mechanisms with key services to support full participation.

### **Internalising the Principles of the Treaty in Organisational Processes**

The responsibilities of service providers which arise from the ratification of the Convention include the requirement to incorporate the principles and core content of the Treaty into the service design, development, implementation and evaluation processes of the organisation.

It is essential that service providers can demonstrate that the services they provide make a positive and significant contribution to achieving the goals of the Treaty. In this regard there are a number of challenges facing service providers. Firstly, organisations need to rethink how they characterise the benefits and impacts of the services they provide not simply in terms of enhanced functional capacity, improved levels of activity and increased participation but also in terms of how the organisation and its services make a real difference in terms of the rights agenda of the Treaty including Civil, Political, Economic, Social and Cultural Rights. This may require not only the rewording of policies and publicity materials but also changes to the way service users are treated, how interventions are delivered, how outcomes are measured and the introduction of new services and modules that directly address the rights of service users within the organisation and externally within the community e.g. introducing a complementary studies module in rights and redress for all service users and their families.

Secondly, service providers must adopt the principles underpinning the Treaty as core organisational values. In this regard the values statement of the organisation should be reviewed and revised where appropriate using a frame that includes:

- Respect and Dignity
- Autonomy
- Independence and Choice
- Non-discrimination including gender and age discrimination
- Valuing difference and diversity including ethnic diversity
- Equal of Opportunities
- Accessibility

Any organisation that has been keeping up to date with the paradigm shift to the social model of disability should have already integrated these principles into to the way the organisation manages its service delivery processes. These principles were not generated especially for the purposes of the Treaty but reflect an approach that has been adopted in national disability strategies over the past 30 years. The main responsibility that this places on service providers is to ensure that the Mission, Vision and Values of the organisation are clearly in line with these principles.

Thirdly, a related aspect of the Treaty that needs to be addressed by service providers is the extent to which staff training programmes, quality systems and practice guidelines conform to the ethos outlined in the Treaty in terms of a culture that privileges the health and welfare of its services users and that enhances their self-respect, sense of dignity and level autonomy regardless of age, ethnicity or gender.

### **Operating on the Basis of a Biopsychosocial Approach to Service Provision**

The Treaty specifically describes an approach to disability that is anchored in a biopsychosocial model of disability in which physical, mental, intellectual and sensory impairments interact in a dynamic way with barriers in society to result in disability. From this standpoint there is a responsibility on service providers to ensure that a biopsychosocial approach to disability is integrated into service design and delivery and needs assessment procedures. It is essential that the biopsychosocial approach is clearly evident in the way needs and strengths are documented, the scope of services offered by the organisation and in the day to day attitudes and practice of staff. This is no easy challenge in that despite the fact that the International Classification of Functioning, Health and Disability has been in

existence for over eight years it is still difficult to discern it in the policies of many Member States, the practices of service providers or the attitudes and methods of medical and health professionals.

### **Adopting a Multidisciplinary Assessment of Needs and Strengths**

The Treaty specifies that the planning and delivery of habilitation and rehabilitation services should be based on a multidisciplinary assessment of needs and strengths. Given that the Treaty specifies what is required of State Parties rather than service providers this should be interpreted to mean that assessment of eligibility for rehabilitation services on the part of the State should no longer be based on a narrow determination of the degree of disability which a person is deemed to have or on medico-diagnostic procedures. For example, simply basing eligibility for habilitation services solely on a diagnosis of Autism Spectrum Disorder would contravene the Treaty. Equally using a severity scale to assess eligibility for vocational rehabilitation may not comply with the Treaty either. In fact most Member States may well be operating assessment processes which do not meet the standards required by the Convention in the fields of habilitation and rehabilitation and this should be highlighted alike by service providers and representative organisations of people with disabilities.

In addition, service providers themselves should lead by good practice and introduce multidisciplinary assessment of needs and strengths as a starting point for person-centred planning and service delivery.

### **Operating as a Best Practice Employer**

Service providers should lead by example in terms of the employment of people with disabilities. This may require a review current recruitment, promotion and retention processes within the organisation to ensure that non-discrimination regulations are strongly integrated. As such organisations should publicise themselves as equal opportunity employers, continually monitor the way in which staff members are developed and promoted within the organisation. In this regard it is not enough to demonstrate compliance by employing low qualified staff with disabilities in a sheltered capacity. It requires that the proportions of people with disabilities at all levels of the organisation are monitored and reported and that the average earnings of employees with disabilities are compared to the remuneration for similarly qualified staff with out disabilities.

Equally, organisations must review how they manage employees without disabilities to protect them from injury or ill-health and to assist them to return to work in the event that they acquire or develop a health related condition which creates a risk to their continuing employment status.

As providers to people with disabilities organisations should also within the constraints of anti-discrimination law, take affirmative actions to increase the number of employees with disabilities recruited by the organisation. This can involve providing work experience to job seekers with disabilities, advertising in places where people with disabilities are likely to see the notice and making sure that physical and cognitive demands of all job roles have been systemically carried out and are on record so that reasonable accommodations can easily be identified.

### **Augmenting Staff Training and Development Processes to embrace the Treaty**

The point at which a service user will experience the impact of the UN Convention within a service providing organisation is in their interaction with its frontline staff. To ensure that the principles and policies of the organisation in this regard are fully deployed in service delivery, organisations must put in place Continuing Professional Development programmes for staff to ensure that they are fully up to date on current best practices in their fields of expertise



and the requirements placed on them by the ratification of the Treaty. During the recruitment and selection of medical and allied health staff the issue of rights should be explored with job candidates. The implications of the Treaty for professionals and service delivery must also be addressed during the organisation's induction process.

There is also an onus on organisations to ensure that as standard within the organisation all staff are properly qualified and accredited to carry their duties as specified within their job descriptions. While this should be a given in any high quality service provider, it can not be assumed particularly in the appointment of staff to auxiliary grades such as care assistants and personal assistants.

### **Operating Secure Health and Personal Information Management Systems**

The Convention explicitly requires Member States to operate information management systems that protect the personal, health and rehabilitation information that has been collected on a person who is or has been in receipt of services. This requires that reporting mechanisms provide for the use of anonymised information only and that when information is being shared with a personal identifier between agencies or between professionals it is done with the explicit informed consent of the individual. The risks inherent in this are escalating as electronic information management systems become more pervasive and interconnected.

This should also apply to those service providers who are operating in fields where the collection and processing of sensitive personal or health information is required for effective service delivery. There is an onus on organisations to review current procedures for dealing with service user information to ensure that the personal, health and rehabilitation information is properly protected and disposed of (or anonymised) within a reasonable period of time.

### **Operating Transparent Procedures for Documenting Informed Consent**

The Treaty explicitly state that participation in habilitation or rehabilitation services should be on a voluntary basis. In interpreting this it should be kept in mind that this has not always been the case for people with disabilities even in some developed societies in the recent history. The issue can be quite complex when working with people who have cognitive or intellectual impairments as a result of congenital, acquired or progressive conditions where capacity to consent may be in doubt. Nevertheless there is a clear responsibility on State Parties to ensure that the public and private health care systems operate on the basis of high ethical standards including obtaining informed consent for all interventions.

There is a clear responsibility for organisations operating in the health, habilitation, rehabilitation and social care sectors to put in place procedures that clearly document that service users are participating in interventions on the basis of informed consent and there is no arbitrary interference with their honour, reputation, communications and correspondence. There are instances where informed consent can be implied based on the circumstances in which the service is being delivered. For example, if a GP refers a person for physiotherapy and the person turns up for treatment, his or her attendance at the clinic implies that he or she has contented to the treatment. Nevertheless it would be timely for service providers to review current consent procedures in the context of the Convention.

### **Reviewing Organisational Policy and Procedures on Abuse and Exploitation**

In parallel with the ethical approach described in the Convention, there is also a strong thread emphasising the need for State Parties to guarantee freedom from violence, abuse and exploitation. One of the strong requirements is to establish a body which is responsible for the Independent Monitoring of Abuse. This requirement on the State must be reflected in

the internal policies and procedures of service providers. No matter how well intentioned an organisation may be, there is no guarantee that within the individual relationship between a staff member and a service user a physically or sexually abusive relationship may develop. There is a responsibility on organisations providing services to people who are potentially vulnerable that the strongest possible protections against individual abuse are put in place.

There is an additional onus on service providers to review current service models to ensure that they could not be perceived to be socially or economically exploitative. This is particularly an issue for organisations operating sheltered and/or supported employment where people are not being paid the full value for their work effort. Finally, particularly in residential settings there must be safeguards against the development of practices that could represent institutional abuse.

### **Introducing Service User Representative Procedures**

A useful mechanism to ensure that abusive practices do not evolve within an organisation is a confidential and easily accessible complaints process where service users can contact an independent support service who can assist them in safely making a complaint about a staff member or practice. This can assist in identifying any areas of concern at an early stage. However, the Convention is based not on passive measures but on the principles of autonomy, independence and choice. As part of this approach the Treaty specifies a role for representative organisations of people with disabilities. Good practice organisations should reflect this by establishing training and awareness modules in citizenship and self-advocacy for their service users to ensure that they can better participate in the representative process and, further, establish, internally, formal procedures for user representation in the design, development and evaluation of services.

### **Adapting Outcome Measurement to reflect the requirements of the Convention**

The onus is on service providers to ensure that the elements of the Convention which rely on service provision are properly highlighted and taken into account in the monitoring and reporting process associated with the Treaty. However, they need to go further and ensure that the services they are providing do in fact contribute to achieving the goals of the Treaty. Without valid and reliable evidence it will be difficult to make this case to funders, policy makers and representative organisations of people with disabilities.

Consequently, service providers need to calibrate the ways in which they measure and report outcomes to bring them into line with the goals of the Treaty. The very least that should be done is to review and revise where relevant key performance indicators to reflect the main aspirations of the Treaty including:

- Physical, cognitive and psychological Recovery
- The level of physical, mental, social and vocational ability achieved
- The extent to which independence has been maintained or attained,
- The degree of inclusion and participation achieved
- The contribution to the economic wellbeing of the service user
- Degree of social integration attained

## **II. A Review of Services indicated in the Treaty**

Inherent in the UN Convention is the view that safe and timely access to appropriate services on a voluntary basis is a prerequisite for the achievement of rights for persons with disabilities. Throughout the text of the Treaty there are references to a range of services but Articles 24 to 28 contain explicit references to a wide range of services, some of which are

traditionally in the public sector domain and some which are often delivered by not for profit providers.

The Treaty Text does not make reference to the distinction between segregated specialised and mainstream services explicitly. Nevertheless there is a strong implication running through the text that people with disabilities have the right to access all general services on an equal basis with the rest of the population. In general the text of each article initially describes the principles of equality and non-discrimination in accessing to services in the mainstream and then, where appropriate, makes reference to other more targeted services that specially focus on the needs of people with disabilities. This is evident in its approach to education which addresses education from the perspective of inclusive education and then elaborates some of the support services that may be required to support a person within mainstream education throughout the lifespan.

For the purposes of this paper Articles 24 to 28 were subjected to a content analysis to identify the scope and range of services explicitly referenced in the text of the Treaty.

The findings are presented from a service provision framework rather than on the basis of the articles per se. For example rehabilitation is referenced eight times in the Convention in four articles but is dealt with under the same heading here.

### **Habilitation and Rehabilitation Services**

The Convention introduces the distinction between habilitation and rehabilitation. This distinction has been around for many years but most systems tend to refer solely to rehabilitation. The difficulty with using a single term to describe both processes is that in many cases while the interventions may be similar the service users and goals differ. Habilitation is used to describe services designed to build the functional and social capacity of people who have had an impairment from birth whereas rehabilitation is about restoring, to the maximum extent possible, a person to his or her previous level of functioning. The goals are recovery and reintegration.

While Article 26 sets out the principles upon which the provision of habilitation and rehabilitation services should be based, there are reference to rehabilitation in the context of health and employment and strong inferences in relation to education and social services. The objectives of habilitation and rehabilitation include both the maintenance and attainment of maximum independence.

The range of services specified by the Convention includes:

- Health-related rehabilitation
- Vocational and Professional Rehabilitation
- Comprehensive Rehabilitation

While specific reference to habilitation is not made in Article 24 there are a number of references to services which could be gathered under the concept including:

- The full development of human potential and sense of dignity and self-worth
- The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential
- Effective individualized support measures
- Programmes to enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community

## **Social Care, Community Support and Independent Living Services**

The role of services in ensuring the equal right of all persons with disabilities to live independently in the community is strongly emphasised in the Convention. Member States are required to take effective and appropriate measures, including the provision of services, to facilitate the full enjoyment by persons with disabilities of their right to an independent life.

There is a very strong imperative in the Convention for the way in which residential services are to be transformed so that all people with disabilities have the right to select their place of residence and with whom they live on an equal basis with others. No individual with a disability must be obliged to live in a particular living arrangement. Compliance with this requirement represents a major challenge not only because of the necessity to develop new services and transition options for those in institutional care but also because this must be achieved while maintaining the quality of life of those in receipt of traditional services. The transfer of resources from traditional to more community based services without a diminution in QOL is a substantial stumbling block that calls for the utmost ingenuity on the part of service providers and funders.

When it comes to the services that are compatible with the aspirations of the Treaty, there are ample opportunities for innovative service providers to take advantage of new opportunities to offer a range of in-home, residential and other community support services. Explicit reference is made within the text of the Convention to the personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community. These services must operate alongside community services and facilities for the general population which are available on an equal basis to persons with disabilities and are responsive to their needs.

The Convention clearly supports the establishment and enhancement of:

- Respite Care,
- Domiciliary care,
- Assistive technology and adaptations to support independent life,
- Community Services,
- Personal Assistance,
- Cultural, recreational and adapted sports,
- Accessible tourism.

## **Employment Services**

The Convention emphasises the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. The Convention makes no mention of sheltered or supported employment services.

The appropriate steps outlined in the Convention include a number of employment services. These are:

- Access to general technical and vocational guidance programmes, placement services and vocational and continuing training,
- Assistance in finding, obtaining, maintaining and returning to employment,
- Opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business,
- Affirmative action programmes, incentives and other measures,
- Work experience in the open labour market;
- Vocational and Professional rehabilitation,

- Job retention and return-to-work programmes for persons with disabilities.

It is clear that specialised employment services can make a major contribution to delivering many of these services. The onus on service providers to demonstrate that the services they provide are the most effective way to deliver on the requirements of the Convention. For example supported employment may well be the most appropriate means to provide assistance to certain people with disabilities to find, obtain, maintain and return to employment. The case must be made by service providers. A first step in this must be to convince representative organisations of people with disabilities, funders and policy of the effectiveness of this approach.

There is a specific reference to access to general, i.e. mainstream, guidance, placement and vocational training services. There is an implication in this that segregated, specialised vocational training and placement services are not within the frame of the Convention. However, vocational and professional rehabilitation are clearly specified and specialised vocational training services are an integral element of an effective vocational rehabilitation system. Once again the onus is on providers of such services to make the case to their key stakeholders that this is the case and to revise their service delivery mechanisms to highlight the rehabilitative benefits of the services.

Disability Management (DM) services are a further example of specialist services that that are not specified but strongly implied. It is up to providers of DM services to make the argument in favour of developing DM as the most effective way to deliver on the requirements within the Convention to assist people to retain their jobs or to return to work after illness or injury.

The provision of segregated sheltered employment is conspicuously absent from the text of the Treaty. In fact there is a very clear reference to an open and inclusive labour market. While this represents a substantial challenge for providers of sheltered employment it is not one with which they are unfamiliar. For many years particularly within a European context the primary role of sheltered employment has been characterised as a transitional process leading people to the open labour market. It is likely that the best way forward for providers of sheltered employment is to re-engineer their services towards work-based vocational rehabilitation, work activation and transition. This is already happening in a number of Member States.

## **Health Services**

The main requirement of the Convention in health terms is to ensure that people with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. In order to achieve this, the State must take all appropriate measures to ensure access for people with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

In addition to rehabilitation a number of other specialised services are implied including:

- Appropriate sexual and reproductive health programmes,
- Health promotion and prevention programmes,
- Early identification and intervention programmes,
- Services designed to minimize and prevent further disabilities, including among children and older persons,
- Disability awareness training for medical and allied health professionals.

The Convention requires that these health services are delivered as close as possible to people's own communities, including in rural areas.

## **Education Services**

The Convention adopts an inclusive approach to education. There is no explicit reference to segregated special education provision. The Convention requires Member States to ensure an inclusive education system at all levels and life long learning in order to fully develop human potential and a sense of dignity and self-worth, and to strengthen respect for human rights, fundamental freedoms and human diversity.

This requires programmes to develop the personality, talents and creativity, as well as their mental and physical abilities of people with disabilities to their fullest potential. At the very least this implies the development of integrated specialised services that are accessible by people with disabilities in a mainstream setting. This implies that providers of segregated specialised education need to build bridges into the mainstream working in partnership with general education providers.

Additionally, it is envisaged by the Convention that people in mainstream educational settings shall have access to the supports they require to facilitate their effective education. It specifies that effective individualized support measures must be provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

In this regard the provision of some elements of special education in segregated settings is appropriate on the basis that the goal is eventual full inclusion. Special education providers must work closely with general education providers to ensure that those who require a period of segregated education can access it and return to the mainstream when this is appropriate. Once again the transitional aspects of specialised provision are central.

Even in the case of complex disabilities such as the deafblind, the Convention does not specify segregated education but requires measures to ensure that it is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

There is also a requirement in Article 24 for the provision of disability awareness training for teachers and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

## **Information, Advice and Advocacy Services**

A theme that runs through the Convention is the provision of a range of information, advice and advocacy services. Many of these imply a deep specialist knowledge of disability and the most effective ways to reasonably accommodate individual differences and needs. It is unlikely that all of these services are currently well developed and so this is an area where there are many opportunities for service providers that have such specialist knowledge to innovate.

The main areas where these opportunities arise include:

- Information, advice and support to employers, educators, health professionals and people with disabilities on non-discriminatory practices and the most effective and appropriate accommodations to facilitate full participation,
- Disability awareness programmes for teachers, health professionals, employers and trade unions,
- Counselling, advice and advocacy services for people with disabilities seeking to access mainstream services,

- Peer support services in which people with disabilities, who have experienced similar challenges and have received appropriate training, provide support and assistance to their peers,
- Services that provide practical advice and training for people with disabilities and their families in the most effective and appropriate assistive and augmentative technologies and devices to enhance participation.

### **III. Opportunities for Service Providers arising from the Convention**

In addition to the service provision opportunities already outlined above there are a number of areas where there is scope for innovation and development.

#### **New Services**

The main areas for innovation arise from the Convention's emphasis on early intervention, recovery, maintenance of ability, community based provision and independent living.

A pre-requisite in this regard is partnership. Service providers must begin to develop mutual working relationships with the mainstream providers that are presented with significant challenges in meeting the requirements placed on them by the Convention. Traditionally it has been difficult to bridge the gap between the mainstream and specialised sectors. However, if the Convention is implemented as it is intended to be, mainstream providers in the health, education and social services sectors will need to be supported to deliver on these requirements.

The organisations that are best placed to provide this assistance are representative organisations of people with disabilities and service providers working in partnership. The advocacy and advice on equal opportunities elements of services can be delivered by these organisations while the rehabilitation and technical aspects can be delivered by service providers.

An important shift in thinking by service providers that will facilitate this evolution is that they must expand their conception of who their customers are. In the context of the Convention mainstream providers, employers and professionals who are required to respond to the needs of people with disabilities are important new customers. This requires the development of new services that specifically target these as end users of the expertise and experience of service providers.

#### **New Target Groups**

The Convention is designed to protect those who have long term physical, mental, intellectual and sensory impairments and who are experiencing disability as a result of an interaction with environmental barriers including attitudes and physical barriers. While there is specific reference to the long term nature of the impairment there are also many references to early intervention, prevention and health promotion that strongly imply that people at risk of long term impairments are also covered by the Treaty. Nevertheless, it is important that this interpretation of the scope of the Treaty is accepted by national policy makers, funders and other stakeholders. The extent to which this approach will inform national disability strategies is yet to be seen and it is not clear that the International Committee will take a similar view. Service providers need to proactively pursue this interpretation with their stakeholders and designated authorities. In the absence of this approach people will continue to develop impairments in the absence of early intervention.

The Convention also specifies a number of other target groups who should be provided with services. These include:

- Older people with disabilities,

- Families and care givers,
- Victims of abuse,
- People with disabilities living in rural areas.

## **New Markets**

In addition to the new services and target groups described above, the Convention indicates that services need to be enhanced in developing countries. It emphasises the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development.

It recognises the importance of international cooperation and its promotion, in support of national efforts for the realisation of the purpose and objectives of Convention and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organisations and civil society, in particular organizations of persons with disabilities.

Of particular interest to service providers, the Convention supports facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices. This offers opportunities to those service providers who wish to expand their remit to become involved in the transfer of knowledge, expertise and services to other jurisdictions. In order to become a part of this process service providers must culture proof their services and actively engage with representative organisations of people with disabilities which are primarily envisaged by the Convention in this respect.

Examples of initiatives which would be welcomed under international cooperation include

- Facilitating cooperation in research and access to scientific and technical knowledge,
- Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.

Given that the responsibility for this resides with Member States in cooperation with international organisations, service providers who wish to take up this challenge must push for this to be a part of the national agenda.

## **IV. Actions to ensure the effective implementation of the Convention**

The High Level Group on Disability has issued two reports on the implementation of the UNCRPD, the latest <sup>2</sup>of which documents the progress being made by Member States<sup>3</sup>. It noted that while there is a wide degree of variation in the stages of implementation and different practices across the Member States, there is nonetheless evidence that all have intensified their efforts in the implementation process.

It also highlights the extent to which Member States have expressed a desire for actions in support of the development a common approach. Including engaging in mutual learning, learning so as to benefit from existing solutions and the development of joint initiatives and coordinating processes particularly in areas where there is shared responsibility between the Member States and the EU. In such cases there is the possibility of establishing a common working forum to generate approaches and solutions that can be shared by those with

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<sup>2</sup> Second Disability High Level Group Report on the implementation of the UN Convention on the Rights of Persons with Disabilities, 2009.

<sup>3</sup> Second Disability High Level Group Report on the implementation of the UN Convention on the Rights of Persons with Disabilities, 2009.



responsibility for the deployment of the Treaty at all levels. One area within the remit of such a forum could be the development of training and awareness raising programmes about rights and redress, and the fostering of leadership skills in people with disabilities so that they can better contribute to the implementation and monitoring process at national and European levels. Service providers should be proactive in seeking to be included in such a working forum or at least contributing positively to its work through cooperation, support and making submissions alongside other members of civil society.

Member States have agreed to report on progress in seven priority areas. Each of these need to be taken on board by service providers and their representative organisations and constructive contributions made to the implementation agenda. A brief summary of each of the priority areas and the potential contribution of service providers are presented below.

### 1. Accessibility

Accessibility actions in the Member States tend to emphasise the built environment, in terms of technical specifications, access to public buildings and in some cases the development of time frames and enforcement measures. Access to telecommunications and in particular web accessibility and accessible transport are also the focus of efforts. In many Member States accessibility is linked to antidiscrimination legislation and the Design for All agenda. There is an acknowledgement by Member States that more information is required about the costs and benefits of investing in the accessibility of education, employment and the economic growth of enterprises.

The contribution of service providers to developments in accessibility can involve not only participating in consultations and public awareness raising but also providing practical solutions for accessibility in terms of widely available ICT training and solutions, ensuring their premises are fully adapted and working in partnership with mainstream providers of education and employment services to develop cost effective solutions to service provision

### 2. Legal Capacity

Guaranteeing the rights of persons with disabilities within the legal system is a complex issue particularly where individuals may be deemed to lack the capacity to understand their actions and the meaning of their rights. This concern arises particularly in the case of psychosocial, intellectual or learning impairments. A pivotal decision can arise where it is necessary for a court to decide on the capacity of the individual and the assignment of a legal guardian or trustee. It is acknowledged that in some Member States current procedures are in need of extensive reform and many Member States have commissioned publications and studies into the most appropriate ways forward.

Service providers have a responsibility to ensure that the solutions proposed in relation to legal capacity are congruent with the needs and entitlements of their service users by engaging constructively in the current debates, raising the awareness of service users and their families of the key issues and implications, providing assistance to service users to defend their rights (including advocacy), making information and advice widely available and including in their programmes modules on self-advocacy and civil rights and responsibilities.

### 3. Access to Justice

Among the issues being addressed by Member States under this heading are the physical accessibility of courts, creating barrier free public buildings (including prisons), providing assistance to people with sensory impairments to participate on an equal basis

(interpretation etc.), training for legal personnel in disability issues and the development of ICT support for participation.

There is a clear gap in service provision in this area in most Member States. In addition to the support services required to ensure that a person with a disability is properly represented in the judicial process, there is the issue of the exclusion of people with a history of offending from current services for people with disabilities. Developing rehabilitation services for offenders which take on board the need to respond to individual impairments at the same time represents a major challenge for service providers but also offers a new target group needing innovative services in terms of preventative and diversionary services for those at risk of becoming enmeshed in the justice systems, those currently held in prison and those making the transition back into the community.

#### 4. Independent Living

The Independent Living agenda is dominant in the concerns of the EU and its Member States. While the majority of persons with disabilities live in the community with their families, in sheltered housing or supported accommodation, about 5% are housed in institutional residential settings. Thus deinstitutionalisation is one of the central areas for action on the part of the Member States where this is an issue. Another key concern is developing more joined up approaches to delivering independent living services and supports both vertically between national, regional and local structures and horizontally between the different actors involved including health, welfare, environment and transport.

As discussed earlier the development of new and enhanced independent living services is crucial to support the aspirations of persons with disabilities to a life of full and equal participation in their communities. Many Member States have concentrated on this area. The most frequently reported services include personal assistance, domiciliary care and integrated health and social care services. Environmental adaptations and the use of ICT to support independent living are also frequently noted. In support of these interventions and supports, changes in the way in which services are delivered are being explored including the use of personal budgets, life-projects, tailored plans and changing the focus from the family to the person

Alongside the development of new services and delivery mechanisms, the enhancement of the quality of both residential and community based services is a central concern. This is being addressed by the establishment of independent authorities, the registration or accreditation of services and the introduction of staff training and qualifications.

One priority indicated by many Member States was the need to develop ways to measure Quality of Life (QOL) outcomes and impacts of these measures.

There are many opportunities for innovation and new service development in the area of independent living, however, there are also challenges. This is particularly so for those providers that are heavily invested in traditional forms of service delivery. Two important contributions that service providers can make to this area are embracing the need for quality standards and developing ways to measure and benchmark improvements in quality of life as a result of service delivery.

#### 5. Voting Rights

Central to civil and political life is the capacity to participate without restriction in the democratic process and in particular to be able to cast one's vote with ease and without the risk of your privacy and right to confidentiality being transgressed. In support of this

goal many Member States are implementing programmes to ensure the physical accessibility of polling stations and of electoral materials. The introduction of ICT support for voting for people with disabilities is one approach.

The main contribution that service providers can make in this respect is to introduce training and support for their service users to assist them to exercise their democratic mandate.

## 6. Monitoring Mechanisms

As described earlier, Member States have responsibilities to put in place a number of mechanisms for the implementation of the Convention. They must establish focal points in Government with responsibility for the implementation process, put in place a coordination mechanism, set up a framework within which the monitoring and reporting process will take place and assign responsibility for independent monitoring to a new or existing entity within the State.

It is essential that providers of services take an active interest in the development and implementation of these mechanisms. Firstly, it is critical that the focal points established include one or more with responsibility for health, education, training, employment and independent living. The way in which these focal points are specified and their terms of reference will have a strong impact on how effectively and coherently the Convention is implemented. There is a risk that a traditional political 'silo' approach will be adopted and result in current fragmentation and gaps being institutionalised under the Treaty. This can be averted both by ensuring that compatible aspects of the Treaty are dealt with by a unified focal point and by putting in place an effective coordination mechanism with strong political support.

It is also critical that the framework which is developed to monitor the implementation of the Treaty clearly represents the full scope of its intention and its content. This requires that the implied and explicit service infrastructure that is needed to underpin the implementation of the Treaty is unambiguously set out in the framework. It can not be assumed that this will be the case given that the role that access to services must play in achieving full participation has only recently been accepted within the equality field.

Finally, the choice of entities to operate as national independent mechanisms within the monitoring process under the Treaty is a matter of concern for service providers and people with disabilities alike. It is important that the mechanisms are truly independent of Government, that they reflect all aspects of civil society and views and that they operate on the basis for the full scope of the Treaty. Service providers must be active in lobbying to ensure that these independent mechanisms comply with international best practice.

Service providers must ensure that the initial National Report to the International Committee reflects the full scope of the Treaty including a review of the adequacy of the current service infrastructure required to support its implementation. The initial report is due two years after the ratification of the Treaty. Service providers need to engage in partnership with representative organisations of people with disabilities to work with national focal points, the coordinating mechanism and independent mechanisms to ensure that the role of services is firmly reflected in the report. The initial report can represent a watershed in the development of new and innovative services and in the continuous improvement of existing services. However, if this opportunity is missed it is likely that the next opportunity will not arise until the preparation of the next report in four years time.

It will be important to ensure that the International Committee for the Rights of Persons with Disabilities truly reflects all perspectives on the rights of people with disabilities including the right to access appropriate services to promote full participation. The initial membership of the International Committee comprises 12 individual independent experts. This will be increased to 18 once the number of ratifications exceeds sixty. It is clear from the wording of the Convention that it is not envisaged that representatives of service providers to people with disabilities will have a specific voice on the Committee. Nevertheless, there are many experts with disabilities who acknowledge and support the incorporation of services into the equal rights agenda. At a national and international level service providers should be active in encouraging State Parties and international organisations to take this into account when proposing candidates for the International Committee.

## 7. Empowerment of persons with disabilities

Under the theme of empowerment Member States have addressed the role of people with disabilities in policy planning and decision-making, the introduction of advisory bodies at national level in which the views of people with disabilities are strongly represented, awareness raising, training in organisational and leadership skills and financial support to representative organisations of people with disabilities.

Being in receipt of services has in the past been associated with dependence and institutionalisation. It is important that service providers redress these conventional perceptions. They can do this most effectively by taking on board the empowerment agenda. They must develop the ability to demonstrate that the services they offer are provided in an empowering manner and that being in receipt of appropriate and effective services is an important factor in contributing to people with disabilities becoming empowered citizens.

Member States have agreed to work through a range of common actions. These include sharing good practice and information exchange on legislation, guidelines and measures through thematic conferences, expert working groups and structured dialogue with civil society. In addition to a special role for the European Disability Forum, there is a strong emphasis on the involvement of people with disabilities in the shared process, the empowerment of representative organisations of people with disabilities and the preparation of persons with disabilities to play a role at EU level.

The core content of the common actions revolves around exploring common challenges facing Member States and sharing existing and possible solutions. Among the main topics addressed are setting minimum standards, agreeing common rules and procedures, developing common reporting formats, indicators and comparable and systematic data collection. In areas where there is shared responsibility between the Member States and the EU cooperation at EU level will be important.

There is very little emphasis in the current approach to common action on the role or contribution of services to achieving the aspirations of the UNCRPD. This is the case despite the fact that the Treaty itself places a significant emphasis on the role of services. At this early stage of the implementation there should be ample opportunities to redress this balance. However, the onus must be on service providers and their representative organisations to pursue this agenda at national and EU level.

Finally, it is critical that service providers collect valid, accurate and relevant data to reflect the needs of people with disabilities, the outcomes of service delivery and the gaps and areas for improvement that need to be addressed both internally by the organisation and externally by the statutory authorities. It is essential that this data is made available in

anonymised format to those who are responsible for monitoring the implementation of the Treaty.

In addition, to ensuring that the Convention is fully implemented nationally, service providers can take a number of other proactive initiatives to ensure that the essential service provision aspects of the Treaty are properly implemented and that they are in a position to contribute productively to the delivery of services in the new context and to develop and expand.

Many of these have been described above but of particular relevance are:

- Active engagement in the process both nationally and internationally,
- Working with international organisations and partner organisations in developing regions to support the deployment of the Treaty and its provisions,
- Aligning internal organisational policies, processes and procedures to the goals and values of the Treaty,
- Working in partnership with representative organisations of people with disabilities to ensure the comprehensive implementation of the provisions of the Treaty,
- Raising awareness and educating service users about how the Treaty can impact on their quality of life,
- Generating evidence and information to support the full implementation of the Treaty and in particular the need for enhanced service provision,
- Adapting existing services and creating new models of provision to ensure that a viable service infrastructure exists as a basis for the effective implementation of the Treaty.

## **Annex 1**

### **Key Articles of the Convention from the Perspective of Service Providers**

#### **Article 19 - Living independently and being included in the community**

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (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 segregation from the community;
- (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.

#### **Article 24 – Education**

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:

- (a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
- (b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
- (c) Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, States Parties shall ensure that:

- (a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
- (b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
- (c) Reasonable accommodation of the individual's requirements is provided;
- (d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
- (e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:

(a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;

(b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;

(c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

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.

5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

## **Article 25 - Health**

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

(a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;

(b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

(c) Provide these health services as close as possible to people's own communities, including in rural areas;

(d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

(e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

(f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

## **Article 26 - Habilitation and rehabilitation**

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States 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:

(a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;

(b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.

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.

## **Article 27 - Work and employment**

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

(a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;

(b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;

(c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;

(d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;

(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;

(f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;

(g) Employ persons with disabilities in the public sector;

(h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;



(i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;

(j) Promote the acquisition by persons with disabilities of work experience in the open labour market;

(k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.

2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.

## **Article 28 – Adequate standard of living and social protection**

1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:

(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;

(b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;

(c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;

(d) To ensure access by persons with disabilities to public housing programmes;

(e) To ensure equal access by persons with disabilities to retirement benefits and programmes.

## Annex 2

### Independent living and Empowerment

#### Two key areas for attention during the implementation of the UN Convention in the EU members' states.<sup>4</sup>

- **Independent living**

Article 19 of the UN Convention recognizes the equal right of all persons with disabilities to live independently and being included in the community. In terms of implementation, this means that Member States shall ensure that persons with disabilities have the right to choose their preferred living arrangements and have access to services and facilities meeting their needs and allowing them to be included in the community.

Data provided by Member States show that the major part of people with disabilities across the EU live in the community with their families or with other types of support (sheltered houses, shared flats, and other forms of community settings). However, in many Member States still around 5% of people with disabilities, mainly with severe mental and intellectual disabilities, live in residential institutional settings. Among these Countries there is a broad consensus towards deinstitutionalisation, and several strategies at national and/or local level have been developed for gradual closure of institutions and the associated placement in community settings. The main challenges to face in the implementation of those strategies are the lack of sufficient resources and the fragmented administrative framework (competences shared between national and regional/local level).

Several alternatives to institutional care are being developed, according to the different stages of the deinstitutionalisation process in the different countries: community based services such as personal assistants, domiciliary care services, as well as the funding of assistive technologies and equipments to adapt houses and apartments. Some Member States provide a number of mechanisms (personal budgets, life-projects, right to choose a personal assistant) aimed at developing tailored care plans integrating health and social care services with a view to extending as far as possible conditions of self-sufficiency. However, most of the financing schemes of assistance are still tailored to the needs of care providers (families or others) rather than to the needs of the users.

A main common challenge is to improve the quality of services both in institutional and community based settings, through the development of quality standards and monitoring mechanisms. To this aim, some Member States have created independent authorities with the task to both develop quality standards and monitor their compliance. In other countries services providers have to be registered and the personnel have to meet special qualification requirements (i.e. special training). However, only little attention seems to have been given to develop mechanisms to measure the impact of these services on the quality of life. Surveys and research are carried out only in a few countries and on a limited scale.

Although there is a broad consensus across Member States on promoting independent living and the deinstitutionalization process, challenges in the implementation of Article 19 vary a lot depending on the different legislative, administrative and also cultural frameworks existing at national level. For this reason it is recommended to have at EU level an exchange of good practices on how to develop quality and cost-efficient community based services and how to empower people with disabilities to exercise their right to independently choose their living arrangements and their care services.

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<sup>4</sup> Extracts from the information note on the national implementation of UNCRPD of the High Level Group on Disability

- **Empowerment of people with disabilities**

The empowerment of people with disabilities is a precondition for the enjoyment of rights and is therefore relevant for the full implementation of the UN Convention. All Member States recognise an important role of persons with disabilities and their representative organisations in the policy planning and decision-making process concerning disability issues. In most countries an advisory body (often organised in the form of a national council) including representatives of persons with disabilities is established and is being consulted by governments when developing relevant policies. In some Member States such consultation is required by law.

Furthermore in order to foster empowerment of people with disabilities, many Member States<sup>5</sup> organise awareness-raising activities, various training as well as provide financial support to representative organisations of persons with disabilities.

Such measures taken at the European scale could be even more effective and would strengthen the empowerment of persons with disabilities. In that context, closer cooperation and exchange of views and practises among Member States but also representative organisations could be encouraged.

Member State's agree that the joint participation of governments, disability organisations and other stakeholders at conferences and meetings to share best practices, as well as a structured dialogue with civil society should be guaranteed and that involvement of actors from the local level (civil servants and disability councils of municipalities) needs to be strengthened.

Promoting and economically supporting programmes for the development of organizational and leadership skills for people with disabilities themselves, as well as organising trainings for persons with disabilities to help them assume leadership roles provided at EU level were suggested as helpful in ensuring that people with disability are empowered.

Member States also agreed that the role of the European Disability Forum at the EU level needs to be emphasised and in this context the co-operation between EDF and the national organisations is vital.

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<sup>5</sup> Examples of good practices: Second HLG Report - BE, DE, ES, FI, HU, IE, NL, PL, SE, UK

## Annex 4

### RATIFICATION PROCESS, SELECTED MEMBER STATES AND THE EUROPEAN UNION AS OF 6 MARCH 2009

		SIGNATURES		RATIFICATION		
	SIGNATURES RATIFICATIONS	AND	THE CONVENTION	THE PROTOCOL	THE CONVENTION	OPTIONAL PROTOCOL
1.	Denmark		30 March 2007			
2.	Estonia		25 September 2007			
3.	Finland		30 March 2007	30 March 2007		
4.	France		30 March 2007			
5.	Germany		30 March 2007	30 March 2007	24 February 2009	24 February 2009
6.	Greece		30 March 2007			
7.	Hungary		30 March 2007	30 March 2007	20 July 2007	20 July 2007
8.	Ireland		30 March 2007			
9.	Italy		30 March 2007	30 March 2007		
10.	Lithuania		30 March 2007	30 March 2007		
11.	Malta		30 March 2007			
12.	Netherlands, The		30 March 2007			
13.	Norway		30 March 2007			
14.	Portugal		30 March 2007	30 March 2007		
15.	Slovenia		30 March 2007	30 March 2007	24 April 2008	24 April 2008
16.	Spain		30 March 2007	30 March 2007	3 December 2007	3 December 2007
17.	United Kingdom		30 March 2007	26 February 2009		
18.	European Community		30 March 2007			