



EASPD Alternative report on the implementation of the UN CRPD by the European Union



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Executive summary

EASPD (European Association of Service providers for Persons with Disabilities) is a European NGO network representing over 10,000 social and health service provider organisations across Europe and across disabilities. Its objective is to promote equal opportunities for people with disabilities through effective and high-quality service systems. We work towards ensuring the full implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD) and are accredited to the Conference of State Parties to the CRPD.

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This report represents the possibility for EASPD to highlight the role of social and health support services for persons with disabilities and how the availability and accessibility of quality services can ensure the implementation of the United Nations Convention on the Rights of Persons with Disabilities.

Service provision in the disability sector has been undergoing substantial changes over the past years, and many services that were set up according to the medical-based approach to disability, are currently moving away from this model towards the social rights model introduced by the UN CRPD whereby needs and preferences of the individual are at the core of the attitude towards disability. These fundamental changes in the services design and delivery are clearly yet to be fully accomplished, at policy and at practical level, and they represent the challenge for the service provision of tomorrow as well as for policy makers at EU and national level.

By means of this report EASPD presents its assessment of the EU report on the implementation of the UN CRPD under Article 35 of the UN CRPD. The report focuses on the articles that are specifically relevant for the support services sector and gives recommendations to the EU on how to improve its positive influence on the development of disability friendly legislation and practices in the European Union in order to further raise awareness, promote models of good practice and ultimately ensure enjoyment of human rights for persons with disabilities.



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List of abbreviations

ANED	Academic Network of European Disability Experts ¹
EASPD	European Association of Service providers for Persons with Disabilities ²
EDS	European Disability Strategy ³
ESIF	European Structural and Investment Funds
EU	European Union
FRA	European Union Agency for Fundamental Rights
NHRI	National Human Rights Institutions
UN	United Nations
UN CRPD	United Nations Convention on the Rights of Persons with Disabilities

¹ <http://www.disability-europe.net/>

² www.easpd.eu

³ COM(2010) 636 <http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52010DC0636&from=en>



Introduction

This report aims at highlighting the importance of quality support services in realising the rights of persons with disabilities as set out in the UN CRPD. Its purpose is to assess the role the European Union has taken in regard to its obligations arising from the conclusion of the UN CRPD by the EU on 23.12.2010.

EASPD

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EASPD (European Association of Service providers for Persons with Disabilities) is a non-profit European umbrella organisation, set up in 1996, currently representing over 10.000 social and health services for persons with disabilities. The main objective of EASPD is to promote equal opportunities for persons with disabilities through effective and high-quality service systems that are in line with the UN CRPD.

The EASPD membership represents disability-related services in the field of education, employment and individualised residential support. Through its members EASPD has considerable expertise and experience across the full spectrum of age and disability.

Since the UN CRPD came into force it has become the core of EASPD's political strategy. EASPD has been since actively contributing to the implementation of the Convention on the Rights of Persons with Disabilities by raising awareness with stakeholders at national and international level and cooperating with its members to constantly improve and innovate services for persons with disabilities in a co-produced way and according to the principles of the UN CRPD. Our members are committed to facilitate human rights enjoyment within the framework of the Convention and to empower persons with disabilities. Individualised tailored made services are the objectives they pursue as these types of services pave the way towards inclusion in society, and they participate in reinforcing social cohesion. The CRPD recognises this role by saying that assistance in relation to inclusion and services are guaranteed by the rights included in the Convention.

Service provision in Europe

Service provision in the disability sector has been organised in different ways according to socio-economic and cultural variables in each country. Services in the past were built and set up by families, by the State and/or by charitable organisations that looked at solutions to provide care of and to keep persons with disabilities in safe and protected environments. Traditionally services were set up with the explicit objective to cure the "illness" of persons with disabilities, hence often being structures that would focus on the "disability" in the first place, rather than the individual's human rights. This was done in line with a medical approach to disability that led to perceiving persons with disabilities as humans with problems, to be treated and/or pitied, without recognising their skills and competences. In recent times the disability sector has faced tremendous changes as service provision is being structured more and more around the needs and the preferences of the individual, becoming more person-centred and individualised. These changes are clearly yet to be fully accomplished, at policy and at practical level, and they represent the challenge for the service provision of tomorrow. By bringing about its social model of rights, the Convention has legitimised this change of vision about disability and has become the lead model for the development of support services for persons with disabilities.

EASPD acknowledges that the level and the quality of service provision may differ from country to country, due to the political, socio and economic models in place. The European Union territory overall has been the birthplace of considerable innovations and models of best practices, where the design and the delivery of services is undertaken in co-production with persons with disabilities. Recently, however, these innovations have been jeopardised by the austerity measures applied to the social sector by several governments, as well as by the European Union, as a result of the economic crisis that has hit Europe. As a consequence many support services have been forced to run their services with reduced staff and other resources, and to provide them to more users⁴. This is clearly putting at risk the positive developments attained so far and is hindering any further innovative developments towards support measures.

⁴ http://easpd.eu/sites/default/files/sites/default/files/PressReleases/eohr_report_0.pdf



The objectives of this report

EASPD strives to have stronger high quality service systems in line with the UN CRPD principles, which could bring benefits not only to persons with disabilities, but to society as a whole.

EASPD cooperates on a regular basis with the European Union in defining the support dimension in the disability sector and wishes to thank the EU for the support it receives and for the trusting relationship developed so far. With this report, EASPD would like to strengthen the mutual learning relationship with the EU by highlighting the potential of support systems and their crucial role in enabling persons with disabilities' to exercise their right to participate in society on an equal basis with all citizens. The European Union has the resources and policy instruments to trigger developments and changes in society. EASPD, supporting and promoting the implementation of the CRPD across Europe, is uniquely well placed both to report back on progress on the ground and to influence the development plans of support services, therefore it can contribute consistently to the European support dimension regarding persons with disabilities.

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EASPD also actively cooperates with stakeholders and networks at national and European level and fully endorses the Alternative Reports on the implementation of the UN CRPD by the European Union that have been produced by the European Disability Forum (www.edf-feph.org) and by the European Network on Independent Living (www.enil.eu).

Considering the poor support dimension currently embedded in key policy tools for the disability sector, such as the European Disability Strategy⁵, through this report we would like to highlight the areas where European policies and practices may need (substantial) changes to be fully compliant with the UN CRPD obligations and to support European Union Member States to start and/or carry on reforms in the disability sector that are CRPD compliant.

This report includes an introduction to the context of the support dimension in disability policies and practices, followed by an assessment of the main articles relevant for the disability support services sector. Each Article analysed includes also recommendations on how to further promote their implementation.

The content of this report is based on EASPD's key position papers, drafted in consultation with its membership and available in the resources section:

- 2014, EASPD, *Making Community-based Services a Reality – Roadmap on Deinstitutionalisation*
- 2012, EASPD *Budapest Manifesto on Inclusive Learning*
- 2014 EASPD *Employment Declaration*.

We are confident that the information hereby provided could be of use to the Committee on the Rights of Persons with Disabilities when assessing the EU Report on the implementation of the UN CRPD, as well as to the European Union in its work in the disability area of policies.

⁵ 2012, EASPD, Support Services : human rights enablers. EASPD position on the European Disability Strategy



1. Social and health support services in the European Union

The support dimension in European policies and legislation

Support services, when adequate and responding to the person's needs, wishes and preferences are often indispensable to promote the individual's autonomy and independence and therefore give considerable help towards inclusion and participation in the community.

Support services may be considered as the backbone of society: whenever they are missing and/or are not fulfilling persons' needs, rights cannot be fully exercised, preventing participation and inclusion in society. For society this remains a challenge to address if inclusive environments are to be created.

In many ways, EU policies and legislation can impact the situation of people with disabilities and their support services. Positive consensus has been established towards the social function of the European Union that they convey, however, there are arguments to consider their correct implementation under threat due to potential unclear interpretations:

- The **Social Investment Package** (2013)⁶ is one of the first legislative packages that recognises the value of investing in the social cause to lift people from poverty, increases support to those who are most marginalized by society and invests in the generations to come. It is also essential insofar as it marks a shift in approach from the European Commission viewing the social sector as an investment, rather than as a cost. However, as it is a non-binding instrument, it may lack effectiveness in implementation, as well as it risks to see little involvement of civil society actors.
- The new **Public Procurement Directive** (2014)⁷ has recognised the specificities of social services in that they invest in improving the quality of life of individuals, by establishing a specific "lighter" regime for them to provide their services. The new Directive comes with a greater discretion for Member States to procure social services or to organise them in a way that does not involve public procurement, however, the newly adopted text may still have negative consequences for the non-profit sector⁸. Indeed, Article 76, setting principles for awarding contracts, doesn't compel Member States to take into account quality and sustainability criteria. This, unfortunately, leaves open the possibility for public authorities to award social services only on a cost-basis criterion. Moreover, Article 76a on reserved contracts for not-profit organisations provides only a very vague definition of these organisations and sets the maximum duration for contracts to 3 years, preventing the continuity of a service.
- **State Aid** is an essential tool to promote and support the employment of persons with disabilities. In 2014, the European Union launched new rules regarding the General Block Exemption Regulation which sets limits and exemptions of state aid to, per say, companies employing persons with disabilities. Generally speaking, we view the new regulation as a positive improvement contributing to the further inclusion of persons with disabilities in work and employment. However, several key issues remain such as monetary thresholds (article 4) or the definition given to sheltered employment, in terms of percentages of workers with disabilities.
- The **European Semester**⁹ gives civil society the opportunity to bring social arguments to the attention of policy makers at both national and EU level. As a tool aiming to support the achievement of the Europe 2020 targets, the European Semester offers an important opportunity to increase the participation of civil society organisations and social partners into both European and national policymaking procedures. However, there is a lack of meaningful consultation of actors at national level, as well as little transparency in the decision-making of the European Semester process¹⁰.
- The **Investment Plan**¹¹ represents the new European Commission's main objective, aiming to strengthen Europe's competitiveness and stimulate investment for the purpose of job creation. The Commission hopes the Investment

⁶ COM 2013 (83) Towards Social Investment for Growth and Cohesion – including implementing the European Social Fund 2014-2020

⁷ Directive 2014/24/EU of the European Parliament and of the Council of 26 February 2014 on public procurement and repealing Directive 2004/18/EC

⁸ http://easpd.eu/sites/default/files/sites/default/files/Policy/PublicProcurement/easpd_position_public_procurement.pdf

⁹ http://ec.europa.eu/economy_finance/economic_governance/the_european_semester/index_en.htm

¹⁰ 2015, EASPD, Europe 2020 and the European Semester Bringing Wellbeing to All?

http://easpd.eu/sites/default/files/sites/default/files/final_easpd_report_on_es_2014.pdf

¹¹ COM (2014) 903 An investment plan for Europe



Plan will mobilise up to EUR 300 billion in additional public and private investment in the real economy over the next three years. If Europe is to achieve its 2020 targets, in particular regarding employment, poverty and social exclusion, it is essential that the European Commission includes a social investment approach within the Investment Plan to strengthen inclusion in Europe and help to unlock the job creation potential in the social and health services sector.

- The **Social Clause**¹² represents Article 9 of the Treaty on the Functioning of the EU and procedurally obliges the European Commission to take into account objectives such as high levels of employment, the guarantee of adequate social protection, etc. However, it is clear that the social clause is abstract, ambiguous and of unclear normative quality, and as such is not binding in terms of its substantive content. Therefore, if the EU is to strengthen its social objectives, as inscribed in the treaty, it is essential that the EU works towards a common understanding and definition of the criteria embedded in the social clause.

The European Commission should use the social clause as a tool with which to integrate its social tools and instruments (Social OMC, EPAP, Europe 2020, European Semester, Juncker Package, Social Impact Assessments, and ESIF) towards developing a common definition of the standards it includes; high levels of employment, adequate social protection, the fight against social exclusion, a high level of education and training and the protection of human health.

- The European Commission is currently negotiating on behalf of Member States on several **Trade Agreements** (TTIP, CETA, TiSA)¹³. As these agreements would affect nearly all sectors of the economy, it is essential that the European Commission involves disabled people's organisations in the duration of the negotiations in order to get a better understanding of the impact such agreements could have on the implementation of the UN CRPD. From a social support services perspective, it remains unclear which areas of the sector are included in the agreement and which are not. As support services play an important role in the implementation of the UN CRPD, it is essential that organisations representing support services for persons with disabilities are meaningfully consulted by the European Commission. As of now, the European Commission is stating that publicly-funded social services are not included in the negotiations. Yet, there are important parts of the sector which are either privately-funded or receiving mixed sources of funding. It is essential that the European Commission takes this into account and analyses the impact of such trade agreements on the implementation of the UN CRPD.

The impact of the economic crisis on the disability sector

Persons with disabilities are more likely than others to suffer from the effects of the crisis, especially those experiencing high dependency needs: poverty, unemployment and social exclusion. Cuts in the social sector, but also to self-directed support measures, hinder the capacity of services to support them at the moment when they need it most.

Support services for persons with disabilities are increasingly struggling to survive, instead of focusing on offering the best possible services to their users. Innovative services are often the first ones to be cut, creating a serious danger of regression towards institutionalised settings. Yet, the number of persons with disabilities, especially persons with high support needs, is rising and their living conditions are getting worse. As a consequence, the need for a strong support infrastructure has never been as high as it is today.

The support services sector is also suffering from human resource shortages and from a lack of qualified professionals. Indeed, care and support professionals are leaving the sector, because it offers poor working conditions and very few attractive career opportunities¹⁴. Professionals now have to work under deteriorating working conditions that put them at a higher risk of burnout or of changing professions. In a time where the demand for support and care services is increasing, it is essential that policy-makers take proactive steps to ensure that the sector receives sustainable and adequate funding, which support the recruitment of skilled staff. Yet it is also important for policy makers to take proactive steps to improve the attractiveness of the sector in order to be able to recruit skilled staff. This can be done supporting the development of social dialogue structures in the sector, where social partners will be able to discuss and negotiate on how to improve the sector's attractiveness and working conditions. This would result in helping to unlock

¹² http://easpd.eu/sites/default/files/sites/default/files/Policy/Newsflash/statement_on_art_9_tfeu_executive_summary.pdf

¹³ <http://easpd.eu/en/content/ttip-threat-quality-social-services-europe>

¹⁴ 2013, Vlerick Business School, HR Strategies and recommendations for improving the attractiveness of the social services sector in Europe. http://www.easpd.eu/sites/default/files/sites/default/files/Policy/Vlerick/gsb_report_easpd.pdf



the important job creation potential in the sector due to rising demand. The current situation is not favourable to end users who should unconditionally receive the support required.

The European Commission encourages cuts to public expenditure, which frequently result in cuts to expenditure on social and health services and social protection measures; at the same time it also wishes the European Union to be a model of inclusiveness. This contradictory approach cannot lead to success. Often the most innovative, person-centred individualised support services suffer the most from austerity policies promoted by the EU. One of the effects of this situation is a tendency towards re-institutionalisation, lack of access to the labour market and to mainstream education.

Social and health support services in the European Disability Strategy

The role of individualised support services is not structurally integrated in the European Disability Strategy (EDS), which is the main instrument of the European Union to implement the CRPD at European level. In the Strategy, social and health support services are hardly mentioned. When talking about services, the main focus of the EDS is to improve the accessibility of mainstream services and products, which is clearly a vitally important objective, but it overlooks the fact that, for many disabled people, individualised forms of support are preconditions for the enjoyment of rights.

The following represent our main concerns on the effective implementation of the European Disability Strategy:

- The EDS is not mainstreamed across EU legislation. This has obviously deleterious effects as it prevents a uniform and consistent approach to disability policies and hinders the promotion of an inclusive society in the EU.
- The role of service provision is not structurally integrated in the strategy, which is consequently reflected in a lack of services perspective in EU policies. This not only contributes to a misperception of the needs of people with disabilities but also, by failing to give due prominence to those needs, it undermines the required collaboration between mainstream and disability organisations. As an example of this, there are no specific references to intellectual disabilities, complex and high support needs and mental health in the Strategy. The Strategy appears presently over-focused on the specific situation of persons with physical disabilities, and this oversimplification omits the needs of many persons with disabilities requiring more substantial forms of support. The “one size fits all” approach to disability adopted in this document is the antithesis of the principles enshrined in the CRPD.
- Persons with disabilities and their support services should be structurally involved in the development of policy plans about disability.
- The EDS is not structurally integrated into the European Semester, perhaps the most important EU policy affecting national social policies and consequently on the well-being of persons with disabilities

RECOMMENDATIONS TO THE EU

EASPD considers the following as crucial aspects that should be tackled by an EU strategy on disability:

- CPRD compliant training of staff in both mainstream and individualised services should be a priority.
- The 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 always be included.
- Ensuring the recruitment and retention of skilled professionals, by improving the attractiveness of the sector and unlocking the job creation potential in the sector.
- Linking the EDS objectives with the European Semester process, to have a real focus on disability matters.

The lack of recognition of the support dimension in the European Disability Strategy is particularly unfortunate at a time of economic austerity. The viability of services is under threat. It should be an EU priority to protect and promote the rights of people with disabilities, and this must also include the provision of quality, adequate, accessible and affordable support services. The transition towards an investment approach instead of seeing services as a cost is not yet achieved. Investment in people is not coherently promoted.



2. Assessment of the UN CRPD articles

This section below provides an assessment of the Articles of the UN CRPD according to their reporting in the *Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union*. The Articles presented below include only those that are particularly relevant for the support services sector.

Article 4 General Obligations

The EU shall take all necessary measures to promote, protect and fulfil the human rights of persons with disabilities. To this end, it has the obligation not only to take legislative, administrative and other measures for their implementation but also to put an end to practices that are inconsistent with the UN CRPD, and to take such measures to the maximum of its available resources in order to achieve the full realisation of the rights under the UN CRPD.

The economic crisis has considerably affected the national economies of the EU. This has not only reduced economic growth but also led to drastic budget cuts in spending in the social sector in particular. The austerity measures have especially bad consequences for social services for persons with disabilities, who are facing worsening conditions and are even often simply shut down. As demonstrated in the study annexed to this report, these services have been facing increasing demands the last few years, while being requested to work with decreasing budgets. As a result, both their availability and their quality have been negatively affected within Member States.

This development has had a direct impact on the implementation of the UN CRPD. Social services can help persons with disabilities to realise their human rights on an equal basis with other people by providing individualised support to them. Considering the budget cuts in spending in the social sector, these services have been deeply affected. In addition, the community-based services that are required to promote their autonomy and participation in society under the Convention have not been established. Even existing social services have been suppressed or, at least, reduced in number. The consequence is that persons with disabilities are not receiving the individual support they need with a view to implementing the UN CRPD and have sometimes no other option than turning to more traditional services when they do exist.

Article 9 Accessibility

Accessibility is the precondition to ensure the full participation of persons with disabilities in society. Obstacles to full participation are not only represented by the physical environment, transportation and ICT, but also by the inaccessibility of human support (services, facilities and adequate support) and technical aids, as well as the availability of alternative communication systems (e.g. easy-to-read language, Braille, sign language, etc.).

Often, the concept of accessibility is barely extended to persons with intellectual disability.

The EU legislation still lacks an overall approach to accessibility; where available, accessibility requirements have a limited scope of action and enforcement mechanisms are missing.

RECOMMENDATIONS TO THE EU

European Union legislation

- The EU directive on Public procurement and repealing 2014/24/EU currently allows the inclusion of accessibility criteria in public tenders. However, current legislation does not make accessibility requirements compulsory.
- The publication of an Accessibility Act, which should concern goods and services of the EU Common Market has been announced in a number of institutional and public events; nevertheless, it is not clear when and if this act will be published and what are the preferences for action of limited scope and enforceability.
- Overall there is a lack of a comprehensive approach to tackle accessibility issues in a comprehensive way. Some progress has been made, but we believe that a stronger commitment from the EU could bring a much stronger



barriers-free perspective in Europe.

European Union institutions

- The European Commission has proposed various initiatives for the accessibility of e-communications and digital technologies. However, with regard to information and communication technologies, many institutional and public websites of the EU continue to be inaccessible in alternative formats. EU institutional, information and communication websites and tools, do not all yet comply with accessibility standards.

How best to use funding streams

- The EU should build on existing expertise at national level, map, set-up and make use of specialized accessibility agencies in the EU that have the know-how to lead and mainstream in the correct way accessibility implementation plans as well as training programmes for professionals in different sectors (e.g. architects, HR managers, decision makers, etc.).
- Promote the “Design for all” concept in legislation concerning new physical environments, services and goods and alternative communication tools such as easy-to-read, Braille and sign language (i.e. through the “Accessibility Act”, etc.)

The role of social and health support services in working with persons with disabilities to overcome barriers should be stressed. The concept of accessibility should be holistic, covering all aspects of life – including human support – and not only access to goods and services. It must apply to all persons with disabilities, including persons with intellectual disabilities, mental health problems and persons with high support needs. Accessibility legislation should take into account the fact that different types of disability can be related to different needs. To this end all dispositions included in accessibility legislation should be detailed enough to avoid misinterpretation against any category of persons with disabilities.

Article 19 Living Independently and being included in the community

The European Union has a shared competence with the Member States for the promotion of independent living and inclusion in the community¹⁵. The right to live in the community involves that States Parties take appropriate measures for the full participation and inclusion of persons with disabilities in society through a range of support services, including personal assistance.

RECOMMENDATIONS TO THE EU

Structural and Investment Funds

The availability of Structural and Investment Funds to support the transition from institutional type of services to community-based services provide a great opportunity to financially help States that do not have the capacity to start the process of change. The European Regional Development Fund (ERDF) provides funding, amongst others, for social and healthcare infrastructure. The European Social Fund (ESF) is an important source of funding for training, job search, coaching, guidance, counselling as well campaigns delivered by social services for persons with disabilities.

The Structural and Investment Funds have however sometimes used to build or renovate residential institutions. In addition to poor monitoring and evaluation, their misuse has led, in some cases, to actions that fail to comply with the rights under the UN CRPD. These funds should be used only to promote equality, non-discrimination, social inclusion and accessibility for persons with disabilities, as required in the ex-ante conditionalities of the new Structural and Investment Funds Regulations (2014-2020).

¹⁵ 2014, European Union, Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union (SWD (2014) 182)



How best to use funding streams

- encourage the use of Structural and Investment Funds to promote the transition from segregating/institutional type settings to community-based ones by i.e.:
 - supporting the creation of community-based services;
 - monitoring the correct use of the Structural and Investment Funds;
 - training professionals on the UN CRPD through e.g. the Erasmus + programme and promote the further take up of the European Care Certificate as one way to improve the quality of support staff¹⁶;
 - supporting service providers to develop and disseminate quality frameworks on community based services;
- identify strategies to deal with the lack of individualised support services that facilitate inclusion and participation in society;
- tackle the issue of cross border service provision (through, for instance, the High Level Group on Disability), unless the geographical distance is minimal and does not prevent inclusion of service users within their local community;
- establish indicators to monitor the transition from institutions to community-based living settings;
- Collect data and analyse targets promoting the transition from segregating/institutional type settings to community-based ones.

The lack of individualised support for persons with disabilities is not only detrimental for the individual's life and personal development but also a clear violation of rights under the UN CRPD. The European Union must put an end to the misuse of the Structural and Investment Funds and strengthen its monitoring and evaluation mechanisms. EASPD would like the EU to strengthen its commitment on this issue by delivering a specific Communication on the transition from segregating-institutional settings to community-based ones and to mark the change required in the design and delivery of service provision and the engagement needed at all levels across sectors.

Article 24 Education

The European Union has only supporting competence in the field of education¹⁷ as well as competences to promote student mobility (via the “Erasmus+” programme). The right to education of persons with disabilities requires that States Parties provide an “inclusive education system at all levels and life-long learning”. They have therefore to take steps to ensure that children with disabilities can participate in general education systems. The EU clearly identifies education as one of the areas of action of the EDS. The EC Recommendation on “Investing in Children: breaking the cycle of disadvantage”¹⁸ also marked an important step forward in recognising the importance of tackling problems at an early stage with a focus on investing on social development.

RECOMMENDATIONS TO THE EU

European Union institutions

While the European Union has limited competence in the education field, it can contribute to implementing the right to inclusive education in various ways. The European Commission can participate in awareness-raising events on the full inclusion of pupils and students with disabilities and promote research in the field of education and collaborate with other organisations in this field. EU institutions can also ensure that the European Agency for Special Needs and Inclusive Education¹⁹ aligns its mandate with the UN CRPD.

Currently, there are a lack of inclusive education programmes for family members of EU civil servants attending European schools. Stronger leadership on the topic should be taken by European institutions to trigger positive developments across the Member States.

¹⁶ <http://www.eccertificate.eu/>

¹⁷ 2014, European Union, Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union (SWD (2014) 182)

¹⁸ C(2013) 778 http://ec.europa.eu/justice/fundamental-rights/files/c_2013_778_en.pdf

¹⁹ <https://www.european-agency.org/>



How best to use funding streams

- promote training and lifelong learning programmes for staff to support the full inclusion of pupils and students with disabilities and developing the Individual Education Plan (IEP) (i.e. through “Erasmus +” and the Structural and Investment Funds);
- encourage the creation of “Universal Design” and comprehensive Learning Curricula in general education systems;
- promote the mobility of students with disabilities in higher education systems through quotas in e.g. “Erasmus +” and support services for students with disabilities;
- map accessible higher education institutions and support services in the field of education in the EU and make this knowledge available among students with disabilities;
- promote accessible vocational training opportunities for persons with disabilities;
- develop qualitative and quantitative research in the education field to identify the physical and social barriers preventing people with disabilities from exercising their rights.

Access to education and lifelong learning programmes in mainstream schools is still far from being the reality for many pupils and students with disabilities. This is due to a shortage of qualified staff, a lack of appropriate accessible buildings, facilities/equipment and widespread and persistent prejudice about the skills and potential of persons with disabilities. The EU could do more to fulfil the right to inclusive education by promoting trainings and programmes which would help staff to succeed in achieving inclusive education and by encouraging Member States to focus on transition from segregated education systems to mainstream schools. Additionally, the EU should strengthen the mandate of the European Agency for Special Needs and Inclusive Education and align it to the principles enshrined in the UN CRPD.

Article 25 Health

The EU has the competence to carry out actions to support, coordinate and/or supplement the actions of Member States with regard to the protection and improvement of health²⁰. The right to “the enjoyment of the highest attainable standard of health” includes both providing equal access to general healthcare programmes and securing access to healthcare services specific for the needs of persons with disabilities.

RECOMMENDATIONS TO THE EU

European Union institutions

Member States have the exclusive competence to define national health policies. However, the European Union can promote research on healthcare for persons with disabilities and support the training of professionals and guidance for support services. It can also facilitate information exchange between Member States on the accessibility of healthcare services, including the promotion of cross-border healthcare services.

How best to use funding streams

Access to quality and affordable healthcare as well as preventive healthcare services should be guaranteed on an equal basis to persons with disabilities, including rural and/or hard to reach areas:

- promote training of first line mainstream professionals in early intervention and long-term care to tackle health inequalities;
- promote actions in the field of health and safety at work to reduce the risk of developing disabilities during working life;
- promote training to make sure that healthcare professionals are able to identify early developmental disorders, to communicate with persons with disabilities and their families and become able to cope with their needs respecting their human rights;
- promote usage of Structural and Investment Funds to provide accessible equipment and technical devices for health facilities;

²⁰ 2014, European Union, Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union (SWD (2014) 182)



- support the development of a disability perspective in mainstream community healthcare services through training of professionals;
- monitor the application of the Public Procurement Directive when procuring equipment or buildings taking into consideration accessibility requirements;

Access to healthcare services by persons with disabilities is often jeopardised by inaccessibility of services and lack of skills to deal with persons with disabilities. The EU can play a role in raising awareness and promoting training opportunities for health care professionals across countries to improve the delivery of services in the healthcare sector according to a human rights framework.

Article 27 Work and employment

The EU has shared competence with respect to the implementation of the right to employment and exclusive competence as regards the compatibility of state aid with the common market and the Common Customs Tariff²¹. The right to work covers the different stages of employment (recruitment, retention, career path development etc.), and requires combating discrimination on the basis of disability and promoting employment of persons with disabilities in the open labour market. The EU clearly identifies employment as one of the areas of action of the EDS. Furthermore, there is an overlap between the UN CRPD and the Employment Equality Directive²², which prohibits discrimination on the grounds of religion or belief, disability, age or sexual orientation in the field of employment and occupation and which recognises the duty to provide reasonable accommodation for persons with disabilities.

RECOMMENDATIONS TO THE EU

European Union legislation

- The EU clearly identifies employment as one of the areas of action of the EDS. The inclusion of persons with disabilities in the open employment market is identified as a priority, yet there is a lack of specific actions accompanying this priority. The particular needs of persons must be better tackled through the recognition of the need for individualised and specialised services in order to provide equal job opportunities.
- The EDS identifies youth as a key group to be supported in the transition from education to employment, however, the key policy instrument that should promote employment for people that have concluded their educational career, the Youth Guarantee, fails to recognise the specificity of persons with disabilities, resulting in indirect discrimination.
- The reference to national/regional measures such as cooperatives and supported employment schemes foreseen by the Strategy indirectly acknowledges the role of support services; however, their role in the development and implementation of these support structures is not further developed. This is a missed opportunity to encourage service providers to use the EDS to deliver more services in this area.
- The EU has adopted the Employment Equality Directive 2000/78/EC, but there has been insufficient monitoring of it and employers and employees lack knowledge about its implications.
- Both the EU Employment Strategy and the Employment Package²³ lack references to the disabled population

European Union institutions

The European Union has shared competence to take appropriate action to combat discrimination on the basis of disability. In addition to legislating, it can make recommendations, promote best practices and facilitate information exchange between the Member States. The European Commission can also participate in awareness-raising events on the full inclusion of persons with disabilities, promote research in the field of employment and collaborate with other organisations in this field. Furthermore, it can provide financial support to programmes aiming at facilitating transition

²¹ Ibid.

²² DIR 2000/78/EC establishing a general framework for equal treatment in employment and occupation

²³ COM(2012) 173 Towards a job rich recovery, <http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52012DC0173&from=EN>



from school to work for persons with disabilities. The European Union can finally ensure that the Structural and Investment Funds are used to support persons with disabilities and facilitate transition to the open labour market.

The EU should lead by example and tackle employment of persons with disabilities within its premises. Only a very small percentage of persons with disabilities are employed within the EU institutions, with an over representation within that group of persons with physical disabilities. The European Union currently does not have a specialised service for the employment of persons with disabilities, nor any specific policy addressing this issue within its bodies. Neither EPSO (European Personnel Selection Office) nor EURES (Job Mobility Portal) address persons with disabilities.

The EU should promote the set-up of a supported employment service to provide guidance to supporting employment services at EU level. Exemplary action should also occur within the EU institutions to support people with disabilities in all phases of their professional career, including by

- introducing supported employment schemes within the EU institutions to promote job opportunities for EU civil servants with higher support needs;
- setting quotas for persons with disabilities;
- promoting internship opportunities for persons with disabilities.

How best to use funding streams

- promote more working opportunities for persons with disabilities in the open labour market, particularly in terms of self-employment and entrepreneurship and employment in public sector;
- promote the availability of individualised and specialised services in order to provide equal job opportunities in the open labour market;
- elaborate on the role of service providers in the development and implementation of national/regional measures, such as cooperatives and supported employment schemes (which are insufficiently developed in the EDS);
- encourage the use of Structural and Investment Funds to support the participation in the open labour market of persons with disabilities and promote training in diversity management programmes;
- monitor the implementation of Directive 2000/78/EC and improve knowledge of its implications for both employers and employees;
- support the working mobility of persons with disabilities across countries of the EU;
- refer to persons with disabilities in the EU Employment Strategy and the Employment Package
- initiate reforms of legal capacity as a barrier to access to open labour market for people with intellectual and psychosocial disabilities;
- the Erasmus + Programme should tackle the promotion and the development of vocational training opportunities for people with disabilities, particularly aiming at a better match of skills and requirements.

The persistent underemployment of persons with disabilities needs to be addressed with immediate action to end the situation of exclusion of persons with disabilities from the open labour market. Support measures are essential to unlock job potential and shift the focus away from impairments on-to skills and competences. The European Union should seek to strengthen cooperation across sectors (including working with trade unions, employers, etc.) and support individualised and specialised services that contribute to opening up the labour market for persons with disabilities.

Article 31 Statistics and data collection

The European Union has shared competence with the Member States to produce statistics²⁴. The obligation involves the gathering of information - including its disaggregation - on the implementation of the rights under the UN CRPD with a view to identifying the barriers to the full participation of persons with disabilities in society.

RECOMMENDATIONS TO THE EU

²⁴ 2014, European Union, Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union (SWD (2014) 182)



European Union legislation

In the EDS, the EC committed to cooperate with EU member states in the collection of statistics and data, in particular with regard to barriers to social inclusion and to indicators to monitor the progress towards Europe 2020 headline targets. Despite relevant initiatives such as ANED and cooperation with EU agencies such as FRA and Eurobarometer, there is still a major gap on data statistics and collections to identify the situation of persons with disabilities within the EU. This is due to the following reasons:

- Lack of quantitative research - EASPD welcomes the creation of ANED, but ANED presents important information on policies and legislations that are more of a qualitative, than of a quantitative nature.
- Non comparable data – due to the lack of a universal definition of “disability” across countries and sectors of activity, data is generally difficult to compare and therefore to use for statistical purposes.
- Lack of a comprehensive approach to data collection - exclusion of persons with disability living in institutions, persons with intellectual disabilities, and persons who do not communicate through verbal speech, all these limitations mean that the data and statistics collected do not completely reflect the overall situation of persons with disabilities in Europe.

How best to use funding streams

- promote the systematic collection of data on persons with disabilities, ensuring that all types of disability are taken into account and that people who live in institutions are also included in the figures;
- assess the needs of persons with disabilities and identify those services that can address these needs following a human rights based approach;
- promote data collection for monitoring the progress towards EU 2020 headline targets;
- carry out research on the correlation between quality of life and quality of services, in order to provide indicators on how to best respond to the individual's needs within a human rights framework;
- promote the collection of data on employment rates among people with disabilities and profiles of unemployed persons with disabilities; moreover, the EU should also tackle the related issues of persons declared unable to work by national legislation, who currently drop out from all available statistics;
- promote data collection on the progress made towards promoting the transition from segregating to community-based settings as well as on the availability of individualised support services that facilitate inclusion in the community;
- collect statistics to assist in assessing the progress made in advancing and promoting inclusive education.

The absence of accurate statistics and data makes it difficult to map and to assess the type of services needed and to plan policies according to the real needs of persons with disabilities. Furthermore it fundamentally underlines any attempt to comprehensively monitor the implementation of the Convention. Research on the correlation between quality of life experienced by persons with disabilities and the quality of services delivered could support the design and delivery of services in line with the UN CRPD principles.

Article 33 National implementation and monitoring

As provided for by Article 33 (2) CRPD, the European Union has set up a framework, including independent mechanism(s), to promote, protect and monitor the implementation of the Convention. The current framework includes roles for the European Parliament's Petitions Committee, the European Ombudsman, the European Commission, the EU Agency for Fundamental Rights and the European Disability Forum.

EASPD regrets that this framework lacks a full representation of civil society organisations and notes that the European Union has not complied with the Paris Principles. These relate to the status and functioning of national institutions for protection and promotion of human rights and are the criteria against the Convention should be evaluated under Article 33 (2) CRPD.

The Paris Principles provide that the composition of NHRIs should ensure 'the pluralist representation of the social forces



(of civilian society) involved in the promotion and protection of human rights” . They also mention a series of categories who should be involved in the work of NHRIs:

- a) Non-governmental organisations responsible for human rights and efforts to combat racial discrimination, trade unions, concerned social and professional organisations;
- b) Trends in philosophical or religious thought;
- c) Universities and qualified experts;
- d) Parliament;
- e) Government departments (if these are included, their representatives should participate in the deliberations only in an advisory capacity) .

RECOMMENDATIONS TO THE EU

EASPD believes that a broader participation of civil society organisations could enrich the composition of the framework and strengthen its impact on the long term in the EU. As explicitly mentioned in the Paris Principles, such organisations include the “concerned social and professional organisations” which are currently not represented in this framework. The Convention strongly affirms the need for cooperation across sectors as a condition to ensure the full participation of persons with disabilities in society. Excluding organisations that are committed to implement the UN CRPD at European level also represents a missed opportunity for cooperation and exchange of expertise in different fields.

EASPD would like to have the composition of this EU level framework revised in order to ensure a pluralistic participation of different civil society organisations according to the Paris Principles.



Conclusions

EASPD is convinced that we need a political agenda to protect and develop the inclusion of disabled people supported by high quality individualised services that are in line with the principles of the UN CRPD. We believe that this is a fundamental human rights issue. Moreover, high quality services are an essential part of an “investment in people” strategy.

For people with more complex or substantial disabilities and their family carers, support services may play a far more significant and influencing role in their lives. So that these services do conscientiously and consistently enable people with disabilities’ to exercise their rights, it is essential that their structure and quality are based on a continuous dialogue with the people using the services and that services are designed and delivered in a co-produced way. A good service provider will do this, ensuring that the services they provide fully reflect and meet the expressed needs and plans of the individual.

EASPD believes in quality accessible, affordable, adaptable, available services that are tailored to the person’s individual needs and preferences. For service providers the requirements enunciated in the UN CRPD call for a re-shaping of how services are provided, the development of new services not currently available to meet new and changing needs and/or the integration in the services of a person centred, inclusive, participative and individualised approach, adopting the social rights model of disability. The development of effective and person-centred support systems requires efforts at all levels of the planning, (re)shaping and development of services that pose inevitably huge challenges for all stakeholders involved in the process. EASPD strives to make sure that support services are delivered applying a person-centred inclusive approach in order to fully meet the users’ needs and preferences and to fully guarantee equal opportunities to disadvantaged people.

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. Moreover, they should recognise the inevitable important role that individualised, tailored made support services can play in the lives of a very significant number of people with disabilities, acknowledging their key contribution in ensuring that the persons with disabilities they support can enjoy their human rights²⁵.

Our key messages to the EU

We call on the European Union institutions and bodies to include a specific service perspective in the European Disability Strategy. We believe that support services for persons with disability can make an immediate and lasting difference to the implementation of the Strategy. In particular, we ask the European Commission to cooperate with us in four areas:

- **Innovation**, to create genuinely inclusive and community based services, through an agenda for change and innovation focusing on services and on how services can implement the EDS and the CRPD
- **Research**, so as to have a clearer picture of the existing services for persons with disability and of their level of compliance with the principles stated by the CRPD, to plan future evidence based research developing the following research areas: the current spectrum and availability of services, funding systems for services, needs assessment, employment opportunities in the open labour market, inclusive education systems and quality of services.
- **The internal implementation of the EDS** within the European Union Bodies as well as the mainstream of the UN CRPD across all EU policies, enabling EU institutions to lead by example about inclusion and accessibility
- **The external monitoring of the EDS**, by including the support services representation.

We have also some proposals more specifically related to the economic and financial crisis:

- **Prevent re-institutionalisation**. Budget cuts from national governments should be well targeted to avoid this, to favour innovative services and foster a better quality in care delivery.

²⁵ 2012, EASPD, Support Services : human rights enablers. EASPD position on the European Disability Strategy



- **Strengthen the role of the social sector.** European governments should promote the attractiveness of the sector by fostering an appropriate lifelong learning framework, good working conditions and excellence in social dialogue mechanisms.

European institutions should put quality at the heart of Social Services of General Interest²⁶. A sector seeking social benefit should not be required to operate under the same rules as enterprises seeking financial profit. The special position of this sector, underpinned by the not for profit motive, should be recognised, respected and protected from inadvertent inclusion in commercially based treaties and agreements. Individualised support services in line with the UN CRPD support and empower persons with disabilities. They accompany service users towards employment; they are paving the way towards inclusion in society, but they also directly contribute to reducing the pressure on social protection schemes. Thereby, they participate in reinforcing social cohesion and full participation into society. For this to happen, EASPD calls on all policy makers across Europe to abandon shortterm artificial measures and to choose the way of long-term sustainability by investing in persons with disabilities.

This report was written by Sabrina Ferraina on behalf of EASPD.

²⁶ <http://ec.europa.eu/social/main.jsp?catId=794>



ANNEX I: Article 33 (2) CRPD EU Level Arguments for Including Service Providers in the Framework

Note commissioned by the *European Association of Service providers for Persons with Disabilities (EASPD)*, Gauthier de Beco, Human Rights Consultant

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June 2012

Introduction

According to Article 33 (2) CRPD, States parties to the Convention should establish or designate 'a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the [CRPD]. When designating or establishing such a mechanism, States parties shall take into account the Principles relating to the status and functioning of national institutions for the protection and promotion of human rights', commonly called the Paris Principles. The legal basis for the establishment or designation of such a framework is therefore Article 33 (2) CRPD. Since Article 33 (2) CRPD refers to the Paris Principles, these Principles are the criteria against which this framework should be evaluated.

The Paris Principles outline the responsibilities, composition and working methods of so-called national human rights institutions (NHRIs). In addition to setting out the functions of NHRIs, they lay emphasis on two fundamental principles: independence and pluralism. Regarding independent mechanisms, the Paris Principles have however to be read in light of the specific mandate of these mechanisms, which is to promote, protect and monitor the implementation of the CRPD.

This note is divided into two sections. The first one provides the legal arguments for including service providers in the framework. The second one illustrates these arguments with State practice in the EU.

1. Legal arguments

The Paris Principles provide that the composition of NHRIs should ensure 'the pluralist representation of the social forces (of civilian society) involved in the promotion and protection of human rights'.²⁷ They also mention a series of categories who should be involved in the work of NHRIs:

- a) Non-governmental organisations responsible for human rights and efforts to combat racial discrimination, trade unions, concerned social and professional organisations, for example, associations of lawyers, doctors, journalists and eminent scientists;
- b) Trends in philosophical or religious thought;
- c) Universities and qualified experts;
- d) Parliament;
- e) Government departments (if these are included, their representatives should participate in the deliberations only in an advisory capacity).²⁸

There is no doubt that the major actors concerned with the promotion and protection of human rights are non-governmental organisations (NGOs). Both NHRIs and NGOs can benefit from their cooperation. On the one hand, NGOs can channel their demands to State authorities through NHRIs, thereby increasing their impact. On the other hand, NGOs can help NHRIs to get in touch with local communities and to be appraised of the day-to-day problems affecting vulnerable groups. NGOs tend however to be over-represented in NHRIs at the expense of other actors, such as trade unions and concerned social and professional organisations, which are mentioned in the Paris Principles on the same

²⁷ Principle 1, B. Composition and guarantees of independence and pluralism, *Paris Principles*

²⁸ *Idem*.



footing as NGOs. NGO dominance leads to forgetting that these actors are also concerned with the promotion and protection of human rights, and that they should therefore be associated in the monitoring process.

As explained above, the Paris Principles should be read in light of the specific mandate of independent mechanism, which is to promote, protect and monitor the implementation of the CRPD. The major actors concerned with the promotion and protection of disability rights are so-called disabled people's organisations (DPOs). These organisations are to disability rights what NGOs are to human rights in general. They should therefore be included in the framework. As already mentioned, the Paris Principles however also refer to other actors. They state explicitly that trade unions and concerned social and professional organisations, which are mentioned in the Paris Principles on the same footing as NGOs, must likewise be represented in the framework. According to these Principles, social and professional organisations concerned with the promotion and protection of disability rights should therefore be included in this framework. Not doing so is not only a missed opportunity but would also dramatically limit the effect of the CRPD by excluding those actors that are closest to persons with disabilities.

In view of this, it is untrue that service providers should not be included in the framework because they are not human rights organisations. Service providers are social and professional organizations concerned with the promotion and protection of disability rights, and they should in consequence be associated in the monitoring process. The Paris Principles, against which the framework should be evaluated, clearly indicate this. DPOs are of course essential actors but they are not the only ones. Including service providers in the framework will moreover enhance the effect of the Convention through mutual strengthening and better coordination between DPOs and service providers.

As far as Article 33 (3) CRPD is concerned, it confirms the important role of DPOs in the monitoring process. Article 33 (3) CRPD is in a way however a repetition of the Paris Principles, which also require that DPOs be included in the framework. As mentioned earlier, the Paris Principles state explicitly that other actors, including concerned social and professional organisations, should be involved in the work of this framework, something which Article 33 (3) CRPD does not contradict. This is confirmed by the term 'in particular' before "persons with disabilities and their representative organizations' in Article 33 (3) CRPD (meaning that other actors should likewise be associated to the monitoring, as provided for by the Paris Principles). Finally, Article 4(3) CRPD does indeed only refer to persons with disabilities but it concerns the implementation of CRPD and not the monitoring process.

2. State practice in the EU

State practice in the EU indicates that actors other than DPOs have been included in the framework. The following examples demonstrate this.

In Austria, in addition to four representatives of DPOs, the Independent Monitoring Committee includes one representative of NGOs, one of development cooperation organisations and one of academic institutions.

In Belgium, the Centre for Equal Opportunities and Opposition to Racism involves actors other than DPOs in the work of the framework. In addition to 11 representatives of DPOs, its Steering Committee consists of six representatives of universities and six of the labour unions.

In Denmark, in addition to five representatives of DPOs, the Danish Disability Council includes seven representatives of other actors including service providers (such as the Danish Housing Association and the Confederation of Danish Industry and Transport). Besides de Danish Disability Council, the framework moreover consists of the Danish Institute for Human Rights (DIHR) and the Danish Parliamentary Ombudsman.

In Italy, in addition to 14 representatives of DPOs, nine of ministries, two of the regions and autonomous provinces and two of local authorities, the National Observatory on the Situation of Persons with Disabilities consists of one representative of the Social Security Institution, one of the National Statistics Institute and eight of social partners as well as three experts.



In Slovenia, in addition seven representatives of DPOs and seven of ministries, the Council for Persons with Disabilities of Slovenia consists of seven representatives of other actors including service providers (one of the Pension and Disability Insurance Institute of Slovenia, one of the Employment Service of Slovenia, one of the Social Protection Institute of Slovenia, one of the Health Insurance Institute of Slovenia, one of the University Rehabilitation Institute, one of the Association of organisations for training persons with disabilities in Slovenia and one of the Association of providers of vocational rehabilitation in Slovenia).

The examples demonstrate that many States have included other actors in their framework, as explicitly provided for by the Paris Principles which Article 33 (2) CRPD refers to. This includes service providers, notably in Denmark and Slovenia. The presence of actors other than DPOs provides for expertise from different perspectives and facilitates cooperation between people working in different sectors. DPOs remain however the major actors concerned with the promotion and protection of disability rights. While other actors are involved in the work of the framework, these organisations keep their predominant position in this framework, thereby avoiding an imbalance to be created in its membership.

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The legal arguments and State practice used in this note provide mainly from the two following documents:

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EASPD (European Association of Service providers for Persons with Disabilities) promotes equal opportunities for people with disabilities through effective and high quality service systems in Europe, representing over 10,000 social and health service provider organisations across Europe and across disabilities. EASPD believes in quality affordable, accessible and adaptable services that improve the quality of life. EASPD works towards ensuring the full implementation of the UNCRPD and is accredited to the Conference of State Parties to the CRPD.



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