

Work Forum on the Implementation of the UN Convention on the Rights of Persons with Disabilities in the EU and the Member States

REPORT¹

On 29 May 2018, the 9th Work Forum on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD, or the Convention), organised by the European Commission took place in Brussels. Similarly, to previous years, the event brought together stakeholders from the EU and Member States who take part in the implementation and monitoring of the CRPD. These are Focal Points, Coordination Mechanisms and Monitoring Mechanisms from the Member States and the EU, along with civil society, disabled people's organisations (DPO) and relevant international bodies. This was the first year when the EU and all Member States ratified the Convention, following Ireland's ratification of the CRPD earlier this year. The Work Forum is an important annual platform to share experiences and promote solutions to common challenges across the EU. This year, the Work Forum focused on three important topics:

- health, habilitation and rehabilitation;
- disability awareness and training programmes;
- and the role of the UN CRPD Committee in implementing the Convention.

This report summarizes the main points and challenges that were highlighted during the Work Forum by the different speakers and participants.

Opening Panel

Manuela Geleng, Acting Director Social Affairs, European Commission, DG Employment, Social Affairs and Inclusion welcomed participants at the Work Forum and presented the European Commission's choice to discuss three key topics that present great challenges for States in the implementation of the UN CRPD. Ms Geleng emphasised that despite the CRPD was adopted 12 years ago, compelling evidence shows equality gaps between people with and without disabilities. The fact that now all Member States have ratified the Convention, should give new energy to carry out the implementation and ensure that persons with disabilities can enjoy their fundamental rights on an equal basis with others. As the European Disability Strategy is coming to an end in 2020, the European Commission is currently assessing how to proceed in the future to implement the Recommendations issued by the CRPD Committee in 2015. There will be a public consultation on the future

¹ This report was prepared by Dr Magdolna Birtha, Rapporteur of the Work Forum.

European Disability Strategy, addressing both the results of the current strategy and upcoming challenges for persons with disabilities and their families. The Commission is counting on the active contribution of civil society organisations and other stakeholders to this consultation.

Geleng was pleased to share that concrete steps have been taken to reach agreement soon on the European Accessibility Act by the Council of the European Union and the European Parliament. Furthermore, in November 2017, the European Pillar of Social Rights was proclaimed and as a social policy framework for the EU, it covers a number of areas that directly impact the lives of persons with disabilities, including the need to mainstream disability in work-life balance and housing policies, provide income support, adapted work environment, or services that support the labour market inclusion of persons with disabilities. The European Commission is committed to implement this Pillar, use it as a framework to implement the CRPD, as well as for the design of the next EU Disability Strategy.

Nadejda Harizanova, Bulgarian Presidency, Ministry of Labour and Social Affairs reaffirmed the commitment of the outgoing Bulgarian Presidency towards the rights of persons with disabilities and their full participation in society. This was also one of the four priority areas of the Bulgarian Presidency in the area of employment, labour mobility and social policy, along with early childhood development, the future of work and the role of the European Social Fund (ESF) in the next funding period Post-2020. In relation to the future ESF, the Presidency organised a conference ‘Investing in people – the way forward’, where they dedicated a workshop on the positive impact of EU funded deinstitutionalisation projects on the social inclusion of marginalised citizens. As Ms Harizanova noted, the implementation of the CRPD is a lengthy process, but States Parties should have a clear vision, a strategy and action plans about how to implement it, across all laws and policies. Equal opportunities, accessibility and non-discrimination policies are indispensable to ensure that persons with disabilities can fully enjoy their rights. The Presidency also started negotiations with the European Parliament on the European Accessibility Act and was committed to progress with this important file.

Gunta Anca, Secretary, European Disability Forum (EDF) complimented the Commission for the choice of topics and emphasised that the UN CRPD is the most important international human rights document for persons with disabilities. There is a strong need to realize the paradigm shift from the medical to the human rights model to disability in the areas of health, habilitation and rehabilitation, and start using human rights language. Awareness raising is an important topic, because there are still many stereotypes in society that are reflected through the media about persons with disabilities.

Ms Anca has called for the ratification of the Istanbul Convention by the EU, as sexual and reproductive rights and health are of great importance for women with

disabilities. Despite the widespread ratification of the CRPD among Council of Europe members, there is some alarming development to introduce a new protocol to the Oviedo Convention, that would allow forced treatment and hospitalisation of persons with disabilities. EDF wants to see a strong European Accessibility Act that covers emergency services, the built environment, obliges also SMEs and last, but not least ensures through including public procurement in the scope of the Act that EU Funds will only be used to develop goods, or services that are fully accessible for all persons with disabilities.

Panel 1: Health, habilitation and rehabilitation in the CRPD

Moderator: **Alarcos Cieza**, World Health Organisation, Geneva

While good health is an important prerequisite to enjoy a good life, there is common reluctance to discuss the issues of health and rehabilitation among persons with disabilities, due to the longstanding dominance of the medical model to disability. Thus, the aim of this panel was to explore how could the human rights model to disability be better mainstreamed in the health sector. The panel also focused on some of the human rights violations that prevent persons with disabilities from accessing health care and the negative impact this has on the quality of their life. There are similar discussions taking place at the UN level, for instance the Human Rights Council requested the High Commissioner to comment on Article 26 of the CRPD (Habilitation and rehabilitation) and this year the topic for the annual report of the Special Rapporteur on the Rights of Persons with Disabilities will be health.

Pirkko Mahlamäki, Board member, European Disability Forum (EDF) (title: Overview on recommendations – CRPD, women, forced treatment) provided an overview about the recommendations the CRPD Committee issued to States Parties on how to improve the implementation of the right to health (Article 25) and the right to habilitation and rehabilitation (Article 26) for persons with disabilities. Measures should include applying a human rights-based approach to disability in the provision of health services, or awareness raising among health professionals about the human rights model of disability (e.g. by integrating this approach in their training curriculum). This means that in line with the Convention, persons with disabilities should not be seen as sufferers of diseases, or a burden on society, but as rights holders, whose medical needs are to be met adequately.

Some of the current challenges faced by persons with disabilities are forced treatment and forced hospitalization, inaccessible health care services and rehabilitation, especially in rural areas, as well as the lack of involvement of the organisations of persons with disabilities in developing health care services. As Ms Mahlamäki pointed out, gender is a significant determinant to inequalities and accessing health care, therefore States should adopt gender sensitive measures, for

example by providing universal access to sexual and reproductive health care services.

Stefanos Grammenos, ANED Expert, CESEP (title: EU health indicators) drew attention to health inequalities and disparities in the EU among people with and without disabilities. The information provided by Mr Grammenos is based on the data Eurostat collects on healthcare, through the EU Statistics on Income and Living Conditions (EU SILC) and the European Health Interview Survey (EHIS). However, the definitions and indicators used in these surveys are not compliant with the provisions of the CRPD (e.g. terminology used is 'persons with limitations'). More human rights based indicators will be needed to measure whether persons with disabilities can access high standard health care and rehabilitation services, as well as support services in the community.

For instance, one of the few EU level health indicators shows, that 1% of people without disabilities versus 34% of persons with disabilities reported that their health condition is 'bad, or very bad'. There is also great difference regarding unmet needs (e.g. due to the lack of available support services) and access to primary health care. When it comes to accessing hospitals, when needed, 1% of the population without disabilities reported problems versus 7% of persons with disabilities, which may seriously impact their general health, or increase morbidity. For future policies, it is important to keep in mind that improving health care services is not enough to tackle the complex disadvantages persons with disabilities face. Specific measures should be put in place to improve their access and satisfaction with health services.

Janina Arsenjeva, Europe programme manager, International Federation for Spina Bifida and Hydrocephalus (IF) (title: Cross-border access to health care) shared the specific challenges people with Spina Bifida and Hydrocephalus face, as they - even with the best health care -, will likely have more often medical needs, than others. In 2015, in the Recommendations to the EU, the CRPD Committee outlined that persons with disabilities face barriers when trying to access health care in another Member State. The EU Directive 2011/24/EU of patients' rights in cross-border healthcare includes some disability-specific provisions (e.g. information to be provided about the accessibility of the hospitals to persons with disabilities, possibility to reimburse extra cost that occurred due to one or more disabilities when receiving cross-border healthcare etc.), however it is not very well known among EU citizens with disabilities and/or chronic conditions and their families. Another problem is that it is up to each Member State to decide whether they reimburse, or not extra costs that occurred due to disability in another EU country. Furthermore, the reimbursement is often low, unequal and uncertain. Ms Arsenjeva concluded that there is a need to improve reimbursement schemes and to raise awareness about the importance of this EU Directive among citizens.

Raquel Castro, Social Policy Senior Manager, EURORDIS- Rare Diseases Europe (title: Rare diseases and disability) presented the challenges that over 30 Million people who live with rare diseases (over 6000 distinct rare diseases) face in Europe, along with their carers. That includes accessing health care, being undiagnosed, difficulties in accessing treatments, uncovered needs, or the lack of work-life balance, just to mention a few. There is a clear shift from considering rare diseases solely as medical conditions towards approaching them as a disability. The reason for this change was the increasing recognition of the fact that the challenges people with rare diseases face rather stem from the socially constructed barriers and negative attitudes, than from their health problems. The lack of recognition also leads to disadvantages in accessing disability benefits for at least 50% of people with rare diseases, especially affecting negatively those with invisible conditions.

Rare diseases also attract more and more attention at European level policy-making. In 2016, the European Commission Expert Group Recommendations to Support Integration of Rare Diseases into Social Policy was unanimously adopted by all Member States. EU initiatives and EU funded projects, such as the European Reference Networks (ERNs) are useful ways to exchange experiences and improve the access to diagnosis and treatment, as well as to raise awareness on the importance of providing high-quality holistic person-centred healthcare for all.

Summary of debate

In the Q&A session, participants asked further questions regarding the definition of 'disability' in EU level surveys in the area of health, with specific focus on how the current definition could be improved to take into account access needs, instead of focusing on the limitations of the individual as an indicator. Mr Grammenos explained that currently there are no better instruments, but ongoing experiments aim to find a new definition and a new concept. It is also very problematic that people who live in institutions and children aged younger than 16 years are excluded from the data collection. It was also unclear whether persons with psychosocial disabilities are covered under the definition 'people with limitations' and if their unmet needs in accessing health care is adequately reflected, or not in the data.

There were questions concerning sexual and reproductive rights, underlining that women with disabilities face serious challenges in accessing medical services, preventative examinations (e.g. mammography) and that some of them would undergo forced sterilization. The speakers emphasised that gender sensitive thinking is crucial, but currently missing from both the health and the disability discourse. The lack of accessible information (e.g. sign language, easy-to-read) also present barriers and exclude many women with disabilities from sexual education. A parent from Romania shared experiences about the lack of public investment in community-

based rehabilitation services for children with disabilities, which isolates them and their families.

Panel 2: Knowing your rights: Disability awareness and training programmes

Moderator: **Nadia Hadad**, Board member, European Disability Forum

The second panel looked into awareness raising and training about the rights of persons with disabilities to different target groups at the national level. Persons with disabilities are still invisible in the media and negative stereotypes prevail the public discourse about them. Article 8 of the CRPD calls States Parties to raise awareness about the rights of persons with disabilities, combat stereotypes and promote positive perceptions across society. While often overlooked, Article 8 is an important provision throughout the implementation of the Convention and to ensure the shift from the medical to the human rights model to disability in the education system, labour market, media, or in society in general.

Luk Zelderloo, Secretary General, EASPD (title: Training, awareness-raising campaign among service providers) presented the work of EASPD and their continued investment in social innovation to improve the quality of services for persons with disabilities and to make them compliant with the CRPD. It is estimated that 8-10 million professionals work at about 20-25 000 organisations in the sector and they need support to understand the complex provisions of the Convention. According to Mr Zelderloo, a good way to raise awareness about the CRPD and the paradigm shift from the medical to the human rights model of disability is to bring innovative practices to the sector and facilitate multi-stakeholder cooperation.

In order to provide person-centred services to persons with disabilities, providers need new HR policies, training on the human rights model of disability, awareness raising about support models (co-production, person-centred planning etc.). At the structural level, there is a need to integrate services and re-organise the systems of support, use quality assurance systems focusing on process and outcomes, apply needs analysis, and develop new services that support the implementation of the CRPD (e.g. respite care, home-help and care, ICT etc.). EASPD firmly believes that persons with disabilities should be at the stirring wheel of innovation in the social care sector, thus the organisations of persons with disabilities are actively involved in their projects, for instance on early childhood care and education, legal capacity, or inclusive community-based planning.

Maria Gómez, Research Associate, Centre for Disability Law and Policy, National University of Ireland Galway (title: Training of professionals on the UNCRPD) provided a detailed overview of the work of the Centre for Disability Law and Policy

(CDLP) at the National University of Ireland, Galway. Among other engagements, the CDLP carries out a number of research projects together with international partners (e.g. Person, Structural Funds Watch, Disability-specific forms of Deprivation of Liberty etc.), hosts an LLM in International and Comparative Disability Law and Policy (full time or part time), organises an annual International Disability Summer School, and promotes the rights of persons with disabilities across the university. The Centre is also providing training to nursing students and legal professionals on assisted decision-making (Article 12 CRPD) and runs a Disability Legal Information Clinic. Ms Gomez highlighted that disability should not be an isolated discipline, but academics and experts from the child rights', or gerontology field should work altogether with disability rights professionals.

Joëlle Desterbecq, Director for Studies and Research, Conseil Supérieur de l'Audiovisuel (CSA), Belgium (title: Analysing the portrayal of disabilities in the media) presented the work of the CSA as the independent authority regulating the audio-visual media services in the Brussels-Wallonia region of Belgium. Among a set of rules that apply to public broadcasters and providers, there is a specific provision that prohibits programmes that include hatred, or violence against various groups, including persons with disabilities. Citizens can submit complaints to CSA in cases, where broadcasters promote discrimination (in 2016, over 160 complaints received, of which 50% concerned discrimination), or when there is a real incitement of violence, or hatred. They also carry out regular barometers to monitor equality and diversity across audio-visual media services. The results of the analysis show that persons with disabilities are very little represented and play mostly a passive role in the media. Furthermore, it is still a taboo to involve them in programmes, outside of those that discuss specifically issues around disability. In order to improve the representation of persons with disabilities in the media, there should be positive messaging, continued research and an open dialogue with the sector. While respecting the freedom of expression, it is important to adopt measures that prohibit hate speech and could ban any incitement to discrimination in audio-visual media, as it is currently hard to take actions against reported hatred, or the negative representation of vulnerable groups.

Csaba Gosztanyi, Managing Director, Carbon Group Communication (title: Hungary: MONDO, an awareness-raising card game) presented the card game, MONDO that covers 10 topics (e.g. 'Do not hurt me!', 'I can live in the community') and teaches children about their rights in a playful and innovative way. The game targets all children between 8 and 12 years old (children with and without disabilities) and wants to ensure that they will become 'rights-conscious' adults. The game was developed in cooperation with the Hungarian Civil Liberties Union, a primary school, a graphic designer, a publisher, and an advertisement agency to create an entertaining game for children with disabilities and their peers in an inclusive environment. The first version of the game was tested with parents and children to ensure that the visualization is appropriate to discuss sensitive topics with them and

teach them effectively about their rights. Besides the MONDO playing card, 'Wonderful Zoli, the Robot', an interactive, 45 mins long stand-up play was also created to increase the empathy of children and make it easier for them to discuss sensitive topics.

Summary of debate

As one of the participants highlighted, children with disabilities are not represented in toy catalogues, so it would be good to know if there are any efforts made with companies to build minimum standards in their advertisement campaigns. Mainstreaming disability across business, housing organisations, or other sectors remains a challenge, however there are some good examples of different actors working together through cooperation agreements, as it was highlighted by EASPD. The CDLP has started to explore how the tourism industry could be more accessible for persons with disabilities and Down Syndrome Ireland has already published an accessible tourism guideline.

As we heard, in Romania the medical model to disability still dominates the discourse in the media and in the social sector. Speakers therefore highlighted that more work to be done to make the legal frameworks CRPD compliant, which have to be respected by service providers and system operators, as well as raising awareness on the Convention. Some participants raised their concerns over the accessibility of the MONDO playing card for children who are blind, or who have low vision. Awareness raising tools and campaigns should be accessible for all and be developed in an inclusive way.

Panel 3: The role of the UN CRPD Committee

Moderator: **Ima Placencia**, Senior Expert, Disability and Inclusion, DG Employment, Social Affairs and Inclusion, European Commission

Every year, the Work Forum also discusses governance issues relating to the implementation of the CRPD. The role of the CRPD Committee is to promote, protect and ensure the full and equal enjoyment of all fundamental rights and freedoms by persons with disabilities by the implementation of the Convention. This timely session discussed some of the challenges the Committee is facing, for instance keeping up with the sheer amount of country reviews, or maintaining a pluralistic membership when it comes to gender balance, or the representation of different impairment types.

The EU had 3 candidates (from Lithuania, Malta and Poland) for the upcoming CRPD Committee member elections on 12 June 2018 and two of them (from Malta

and Poland) presented themselves in this session. European members, can play an important role during the review of other EU Member States, building on their understanding of Europe-specific issues.

Birgit Van Hout, Regional Representative for Europe, UN Human Rights Office (OHCHR), (title: Human rights committees in practice) underlined that with Ireland ratifying the CRPD recently, the EU and all its Member States showed tremendous political will and support to implement the Convention in Europe and eradicate discrimination against persons with disabilities. Ms Van Hout presented the work of the ten UN Treaty bodies that carry out the periodic reviews of States Parties. These treaty bodies have two main functions: to assess progress and issue recommendations after a constructive dialogue with the State party; and to examine complaints from individuals. While the implementation is a complex process, General Comments as authoritative interpretations provide further guidance to States on how treaty provisions shall be implemented. Notably, they are sometimes also referenced in case law by the European Court of Human Rights, however there might be some inconsistency with the jurisprudence of the different Treaty Bodies on the same topics. It is becoming more and more challenging for the Committees to review the increasing number of State reports and to handle the increasing number of individual complaints without a backlog. Challenges also relate to gender and geographical representation within the elected membership of the Committees.

The year 2018 is the 70th anniversary of the Universal Declaration on Human Rights, but the goals and aspirations of the Declaration are not yet achieved. In light of the on-going EU budget discussion, Ms Van Hout reminded participants that investing in human rights, whether financially, politically or morally is essential and should not be a secondary consideration after security and border control.

László Lovászy, Independent Expert to the United Nations CRPD Committee (title: The role and work in the UN CRPD Committee) as member of the CRPD Committee since 2012, provided some very useful insight to the work of the Committee. It carries out the periodic reviews of States Parties, including the constructive dialogue with delegations of the governments, oversees the individual complaint mechanism under the Optional Protocol to the CRPD and issues General Comments to support States Parties in understanding and implementing the provisions of the Convention. The Committee's aim is to carry out the evaluation along equal, but not the same standards, in line with the economic, social and political situation of the States. While the CRPD does not create new rights, but new standards in terms of reinforcing and complementing existing human rights treaties, there are some interesting developments regarding ICT related references in the jurisprudence of the Committee. Mr Lovász'y reminded that accessibility and the removal of physical and social barriers are the backbone of the Convention.

The Committee works along some agreed principles, including clear expectations, fair handling, consistency, and equal evaluation. Mr Lovász mentioned some of the main challenges in the work of the Committee, such as the lack of time, consultations and preparedness. He also highlighted that NGOs sometimes face challenges to follow the process and provide the relevant information on time to the Committee. In the future, it would be important for the Committee to identify problems in advance, improve cooperation with NGOs, and maintain motivation.

Michael Debattista, Assistant Manager Projects and Research, Commission for the Rights of Persons with Disability (title: Malta) as the Maltese candidate for the election in the CRPD Committee and President of the NGO Breaking Limits, presented his 10 years' experience in disability rights activism. He was involved in the working group that produced the first Maltese national policy on the rights of persons with disabilities. Malta is currently making great progress on implementing its UN CRPD Bill and the National Disability Strategy. As part of these efforts, the government put an open call for applications out for the CRPD Committee candidacy, targeting specifically persons with disabilities with strong academic and practical background, as well as understanding of the social model of disability. This is a good example of a transparent and inclusive process to find the best candidate who could represent Malta in the CRPD Committee.

Dobroniega Trawkowska, Associate professor at the Adam Mickiewicz University in Poznań, Institute of Sociology, Department of Research on Social Problems and Social Work (title: Poland) as the Polish candidate for the elections to the CRPD Committee, presented her background as an academic and social worker with over 25 years of experience in supporting persons with disabilities, professionals and giving lectures to university students on the rights of persons with disabilities. She emphasised the importance of establishing systems of support that would prevent discrimination of persons with disabilities and their families. Furthermore, it is necessary to shape public social policies concerning persons with disabilities and change the attitude of professionals by showing them good practices about person-centred, community-based support systems.

An-Sofie Leenknecht, Human rights coordinator, EDF (title: Users' views on the CRPD committee) explained the different ways how the organisations of persons with disabilities (DPOs) can engage in the monitoring of the implementation of the CRPD, not only at national level, but also at international level, through engaging with the CRPD Committee and other human rights treaty bodies (e.g. input on the situation of persons with disabilities, drafting General Comments etc.). More concretely, the European Disability Forum works with EU and non-EU countries (e.g. in Western Balkan) and helps them to draft alternative reports, proposals for the list of issues, or by bringing DPOs to Geneva, so they can meet with the Rapporteur responsible for their country. The aim is to make the process inclusive for all persons

with disabilities, including women, children, LGBTQI people, those living in rural areas, or who face multiple discrimination.

Ms Leenknecht emphasised that training and capacity-building for local disability organisations is key to ensure their meaningful engagement with the UN mechanism. For instance, EDF together with the OHCHR Brussels office and Equinet trains DPOs from countries that come up for review in the next 2 years and also facilitate peer support amongst DPOs. The experiences of EDF show that national disability movements were strengthened thanks to the review process and there are some good examples, for instance the establishment of a national umbrella DPO as a concrete outcome of the UN review (e.g. in Bosnia-Herzegovina).

In 2018, Poland, Malta, Bulgaria and Macedonia (FYROM) will have constructive dialogues with the Committee. Regarding the outcome of the elections organised at the UN CRPD Conference of States Parties on 12th June 2018, EDF would like to see gender and geographical balance, independent and highly qualified experts in the Committee, who represent people with different impairments.

Summary of debate

During the discussion, there were questions regarding the follow-up of the implementation process, once the Concluding Observations of the Committee are published, and regarding the process to get elected in the Committee. Ms Van Hout agreed that there is a lot of energy put into the review process, but it is more difficult to put continued pressure on governments to implement the recommendations of the Committee. Mr Lovász explained that candidates should have a clear vision and strategy for their campaign, show great understanding of the national and regional problems around disability to convince diplomats about their abilities to be a good representative of those issues in the Committee. Indicating impartiality and a neutral approach is essential to get the support of diplomats.

Other questions concerned the challenges some deaf organisations face when trying to engage with the national disability councils during the monitoring of the CRPD, or the lack of close cooperation between National Human Rights Institutions (NHRI) and the CRPD Committee during the review processes. EDF tries to involve deaf organisations in the trainings they give at national level to DPOs. The shrinking civic space, inadequate public funding and the lack of meaningful involvement of DPOs at national level often discussed at the General Assemblies of EDF. The real question is how to ensure that there is enough space for DPOs and civil society organisations don't have to be afraid of engaging with UN mechanisms. Mr Debattista said that it is important to avoid tokenism and provide people with reasonable accommodation and training, so they can participate in an active and meaningful way.

Closing Panel

Ima Placencia, Senior Expert, Disability and Inclusion, DG Employment, Social Affairs and Inclusion, European Commission thanked speakers and attendees of the Work Forum for their active participation. This year, once again, the Commission chose three topics that present great difficulties in the implementation of the UN CRPD at national and European level. Equal access to healthcare, habilitation, rehabilitation, or other services remain a challenge for most persons with disabilities, due to the lack of accessibility, affordability and availability of these services. Mainstreaming disability across different areas and professions and raising awareness about the rights of persons with disabilities are key steps in the implementation process. DPOs have been actively engaged in this year's Work Forum, but it is also important to involve other actors, such as the focal points, or NHRIs in future discussions.

Based on today's discussions, future topics for the Work Forum could include: the future EU Budget Post-2020 and its implications to the implementation of the CRPD (e.g. on financing social services), legal frameworks and assessment tools to implement the Convention, children with disabilities, sexual and reproductive rights, more discussions on data collection and indicators, and on the paradigm shift from the medical to the human rights model of disability.

Pat Clarke, Vice-President of EDF underlined that after the ratification of the CRPD, Ireland will be more active in future Work Forums and that will hopefully revitalize the implementation of the Convention at European level in general. Implementation is a long and complex process, however there is a need for political will and clear plan on how to fully implement the CRPD. The CRPD Committee plays an important role in this regard, so the upcoming elections will hopefully bring a more gender balanced Committee. Unfortunately, the proposed Additional Protocol of the Oviedo Convention shows that there is a lot of fragmentation in the human rights system and the adoption of this text would in fact significantly hinder the implementation of the CRPD.

EDF calls the EU to adopt a new disability strategy with a budget allocated, which should be integrated in post-2020 EU Strategy, become the driving force of a new disability rights agenda and support the implementation of the European Pillar of Social Rights, as well as the Sustainable Development Goals (SDGs).

Andreas Reinalter, Austrian Presidency, Deputy Head of Unit, Federal Ministry of Labour, Health, Social Affairs and Consumer Protection complimented the organisers of the Work Forum for creating a forum to exchange ideas and good practices that can help improving the situation of persons with disabilities. The CRPD has already triggered important changes at national level by developing human

rights-based policies for persons with disabilities, but more progress and indicators are needed to achieve fully inclusive societies. Mr Reinalter said that the debate on the role of the CRPD Committee is an important one, because all actors need to have a clear understanding of their respective roles.

The Austrian Presidency will work under the subsidiarity principle and look at what can be done at the EU and what at the Member States level. In light of the upcoming Brexit and the shrinking EU Budget, Mr Reinalter highlighted that funding gaps in the next EU Multi-Annual Financial Framework should not affect those citizens, who are already disadvantaged. Digitalisation is a great priority for the Presidency, so an Informal Council meeting for Ministers of Employment and Social Affairs will discuss digitalisation in relation to the world of work. The Austrian Presidency is committed to focus on the needs of persons with disabilities and agrees that EU money should be spent for initiatives that aim to include them in society. The Presidency is open to continue the discussion with civil society about the implementation of the CRPD.

Executive Summary

The 9th edition of the Work Forum was a great opportunity to take stock of the implementation of the UN CRPD and to move on and think ahead how to overcome the existing equality gap between persons with and without disabilities. After Ireland ratified the Convention earlier this year, the EU and all Member States are now States Parties to this important human rights treaty. During the past year, there was steady progress at European and national level to implement the Convention and ensure that persons with disabilities and their families can enjoy their rights on an equal basis with others. It was a busy year for the European Commission: there is an ongoing assessment on how to proceed with the European Disability Strategy Post-2020 and they are looking into how to use the European Pillar of Social Rights as a basis for the next disability strategy. The European Accessibility Act is an extremely important legislation to implement the CRPD and will hopefully be adopted soon. While the implementation of the Convention is a long process, policy makers, civil society organisations, DPOs, National Human Rights Institutions and other stakeholders need to work together and exchange experiences between the national and EU level effectively.

This year, participants of the Work Forum discussed some key challenging issues in the areas of health, habilitation and rehabilitation; disability awareness and training programmes; and the role of the UN CRPD Committee in implementing the Convention. Unfortunately, the medical model to disability is still the prevalent approach to collect data in the area of health care and the definition in use is not in line with the CRPD. However, available data shows inequalities between persons with and without disabilities, as well as great challenges around the availability, affordability and accessibility of health services for persons with disabilities. There

are also challenges to the enjoyment of cross-border access to healthcare services, which should be addressed to implement Article 25 and 26 of the CRPD. Healthcare and social care professionals would need training and awareness raising on the CRPD, so a module on the human rights model to disability should be part of their training curriculum. We heard that people with rare diseases are often not considered as persons with disabilities, however they face significant challenges due to many socially constructed barriers. On a positive note, EU funding already supports important projects, for instance to advance holistic high quality care and services for people living with rare diseases in EU.

It was important to hear the experiences of portraying persons with disabilities in the media, as the way the media sees persons with disabilities often reflects existing stereotypes and is exactly how society sees them. Persons with disabilities are very little represented and play mostly a passive role in the media, it is still a taboo outside of programmes that discuss specifically issues around disability. It is important to continue raising awareness across all sectors and adopting measures that prohibit hate speech, or violence against persons with disabilities in audio-visual media.

Undoubtedly, the UN CRPD Committee plays a major role in the implementation of the Convention and in guaranteeing the rights of persons with disabilities worldwide. It was noted that the Committee is facing some challenges to keep up with the sheer amount of country reviews and to maintain a pluralistic membership when it comes to gender balance and the representation of different impairment types. The EU has three candidates for the CRPD Committee member elections in June and ideally there are always some European members in the Committee, who can then play an active role in the review of other EU Member States and the EU itself, building on their expertise and understanding of the European context.