



EUROPEAN DAY OF PERSONS WITH DISABILITIES

Celebrating 10 Years of the UN Convention on the Rights of Persons with Disabilities

2016 Conference Report

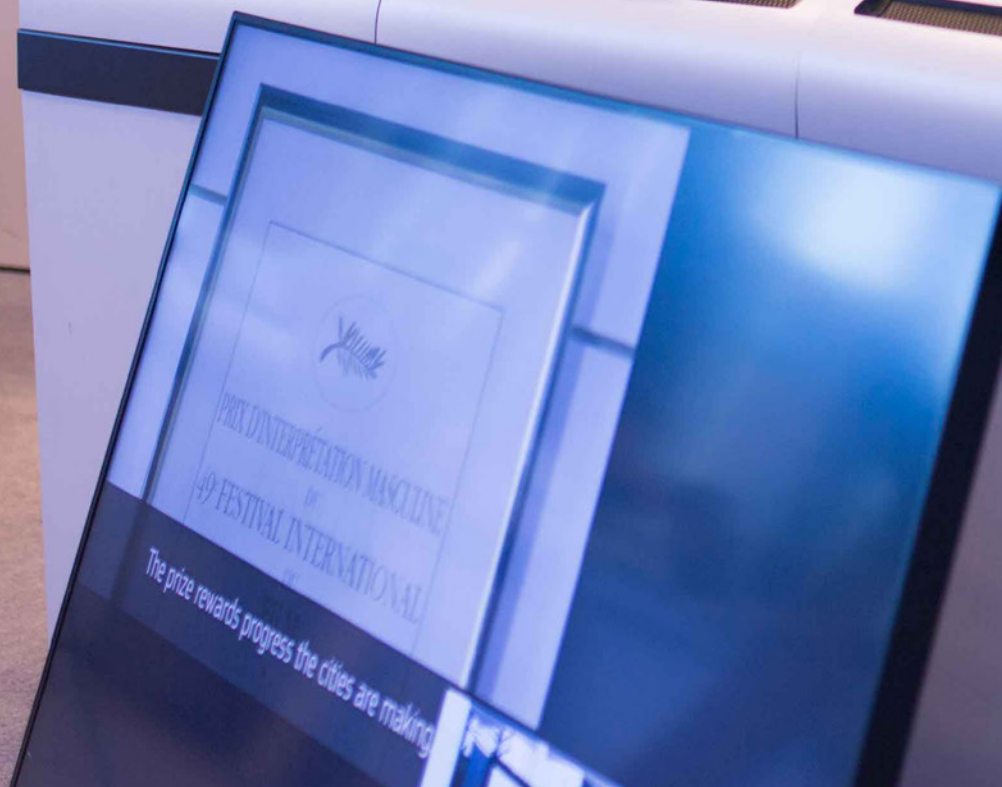
Brussels, 29th & 30th November 2016

Rapporteur: Mary O'Hara



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EXECUTIVE SUMMARY

The European Day of Persons with Disabilities Conference which was held in Brussels on the 29th and 30th of November 2016 was a unique opportunity to mark the 10th anniversary of the UN Convention on the Rights of Persons with Disabilities (UN CRPD). The Convention milestone was acknowledged throughout the two-day event when delegates from across the European Union celebrated the progress made over the past decade and also explored ways in which rights could be boosted and further improved for all people with a disability.

The landmark event placed a firm focus on the role of the Convention and its implementation within the EU in ensuring equal opportunities for all persons with disabilities, active inclusion and full participation in society. Co-organised with the European Disability Forum, the annual conference is part of wider EU efforts to promote mainstreaming of disability issues in line with the UN CRPD, to which the European Union and the majority of its Member States are parties, and also in line with the eight areas of the European Disability Strategy 2010-2020.

A broad and interesting combination of presentations, discussions and debates characterized the conference with the views and insights of persons with disabilities paramount throughout. Five separate and diverse panels examined various aspects of the UN CRPD as well as its wider impact. Panel sessions had lively and informative contributions from the conference hall.

Those attending included people from a range of disabled people's organisations (DPO's) and from various countries as well as local, national, European and international organisations, advocates, academics, government and EU institution representatives. The event was live-streamed to an international audience with social media being used to encourage further participation and interaction.

Highlights of this year's conference included accounts from persons with different disabilities referencing how the Convention has affected individuals, communities and wider society. Many of those who spoke used the occasion to focus on specific challenges that remain to full inclusion ranging from freedom of movement and accessibility to deinstitutionalization and independent living. Discussions around the frameworks already in place and those in development aimed at assuring the fundamental rights of people with disabilities in the future featured prominently.

Many participants emphasized the connections between the wider human rights agenda and the movement for the rights of persons with disabilities. The crucial goal of mainstreaming disability throughout society, and across all policy areas, was raised repeatedly by delegates and speakers.

Stimulating and engaging exchanges took place regarding developments such as the European Pillar of Social Rights, the European Accessibility Act and specifically the Commission's EU Disability Card initiative. Other focal points included the interconnection between poverty, social exclusion and disability, the experiences of women and girls with a disability, the need for direct input by persons with disabilities into policy-making, and the importance of ensuring effective monitoring and enforcement of rights across Europe.

Practical suggestions for how to fully implement and improve upon the UN CRPD in the future were made both by panelists and audience members.

A new feature of the 2016 conference was the participation of team coach **Stien Michiels**. Ms Michiels acted as an 'ice-breaker' facilitating introductions on day one and, along with animator, **Muriel Orange**, on the final day presented issues raised by delegates through performance art.

A number of themes and issues emerged during the conference. These are addressed throughout this report.

Key themes included:

- Assessing the positive impact of UN CRPD and identifying the challenges remaining.
- Placing the rights of persons with disabilities within the wider human rights agenda.
- The persistence of the medical model of disability and how to address it and focus on the human rights approach.
- How to ensure that the rights of persons with disabilities are fully mainstreamed.
- Tackling ongoing barriers to accessibility and full inclusion, including institutionalization.
- Addressing high levels of poverty, unemployment and social exclusion.
- The urgency of prioritizing the distinct issues facing women and girls with disabilities.
- Ensuring that the crucial goals of independent living and freedom of movement are met.
- The vital role of direct input by persons with disabilities into policy-making and implementation.
- Exploring how the human rights of persons with disabilities are protected by Member States.
- Pursuing effective data collection, monitoring, and enforcement of rights across the EU.
- The importance of utilizing existing EU frameworks and mechanisms as a push to progress.
- The ongoing fallout of the financial crisis and austerity policies.
- Developing a new European Disability Strategy for the next decade.





DAY 1



DAY ONE:

OPENING SESSION

Introductory speeches by Michel Servoz, Director General for Employment, Social Affairs and Inclusion, Yannis Vardakastanis, president of the European Disability Forum & Eva Hodges, social policy attaché, Permanent Representation of the Slovak Republic to the European Union.

Taking stock of the UN CRPD - accomplishments and challenges

“This year’s conference is special. It is special because the United Nations Convention on the Rights of Persons with Disabilities was adopted 10 years ago. It brought hope to a billion people with disabilities worldwide. It is clear that the UN Convention has brought a new understanding on the concept of disability.”
(Michel Servoz)

As the first speaker to address the conference on the opening morning, **Mr Servoz** began by telling attendees what an “outstanding” achievement the UN CRPD has been so far, and of its central role in shaping the European Disability Strategy 2010-2020. He took time to inform delegates about the public consultation of the Strategy commenting that the process had been extremely informative and that a report would be published in early 2017. The report is on the first five years of the implementation of the European Disability Strategy 2010-2020. He also emphasized the need to continue to deliver on the objectives of the Strategy in the eight action areas, taking into account the follow-up to UN Concluding Observations.

Putting the conference in a wider context **Mr Servoz** stressed the many challenges currently facing the EU – all of which have an impact on the rights of persons with disabilities. These included globalization, an ageing population and the aftermath of the financial crisis. Meeting these challenges was vital for ensuring full inclusion and, he said, the European Pillar of Social Rights was a significant step towards this. He encouraged those taking part in the conference to contribute to the Social Pillar consultation process.

Mr Servoz said of the Pillar:

“This is a way to prepare the European Union and citizens for the future and 21st century.”

Mr Servoz presented a sense of what the panels and discussions to follow would address when he highlighted the fundamental rights of persons with disabilities to self-determination, full inclusion, accessibility, independent living and freedom of movement. He also remarked on the importance of initiatives such as the European Accessibility Act (EAA), the Youth Employment Initiative and the Youth Guarantee while emphasizing the need for identifying and addressing the myriad issues persons with disabilities face daily, including access to employment.

In his opening session speech on behalf of the European Disability Forum (EDF), **Mr Vardakastanis** outlined the organisation’s view on the implementation of UN CRPD across Europe and its ongoing impact on disability rights. He called on everyone to “never underestimate” the significance of Europe adopting the Convention. The impact has been considerable across many areas of policy that affect the lives of persons with disabilities, he pointed out. Nevertheless, he added, big challenges remain.

Mr Vardakastanis told the conference:

“Europe today is in a period of critical developments. And the CRPD can be used as a positive narrative for the 80 million Europeans with disabilities, to strengthen the European project in their minds and in their lives.”

Mr Vardakastanis explained that EDF wished to put forward a number of proposals that would build upon the Convention and on existing rights. Among those he mentioned was a call for a renewed focus on reviewing and monitoring the implementation of the Convention and for a need to start preparing the 2030 disability rights agenda. He also proposed that 2021 be the European Year of Disability Rights.

Mr Vardakastanis concluded:

“This is the time to work. This is the time to break the barriers of the past.”

Bringing the commencement speeches to a close **Ms Hodges** stressed that fundamental rights should be afforded to persons with disabilities everywhere. She praised the European Accessibility Act as a vital step in the right direction and summarized efforts by the Slovak presidency to prioritize the rights of persons with disabilities in the EU during its tenure.

Ms Hodges highlighted work taking place on the impact of poverty, disadvantage and social exclusion on persons with disabilities. She also drew attention to overlaps between persons with disabilities and various vulnerable groups within society in terms of disadvantages. Ms Hodges referred to a report by the European Institute for Gender Equality, which “showed that people with disabilities belong to vulnerable groups, but face higher risk of poverty.”

Of the conference **Ms Hodges** concluded:

“The Slovak presidency considers the conference as a milestone in an effort to promote, protect and ensure the full and equal inclusion of all persons with disabilities.”

Before the first panel of the day began, facilitator **Stien Michiels** took ten minutes to encourage delegates to get to know one another and to engage in conversations throughout the event. **Ms Michiels** also reminded attendees of the importance of taking part in the discussions and debates after each panel. She distributed ‘post-it’ notes around the room and requested that people write down comments or ideas they had so these could be shared with others at a later point.



PANEL ONE – 10 Years of the UN Convention: From Medical Model to Human Rights Model of Disability

The members of this panel were: *Catherine Naughton: Director of the European Disability Forum and moderator of the panel; Gunta Anca: Vice President, European Disability Forum; Maria Soledad Cisternas Reyes: UN Committee on the Rights of Persons with Disabilities.*

Moving forward –Using the UN CRPD and related initiatives to advance rights

During her time as an advocate for the rights of persons with disabilities **Gunta Anca** has often been asked the same questions: ‘Why do we need a special convention? Maybe we can make it a human rights declaration?’ **Ms Anca** told the conference her response to such questions has been this: “No, it is not possible because there are so many very special things people with disabilities need to reach the same rights and same opportunities that everybody else has.”

Speaking from personal experience as well as in her role with EDF, **Ms Anca** stressed the significance of the Convention. She also emphasized the importance of ensuring that the medical model of disability is replaced everywhere by a human rights model. **Ms Anca** spoke about how legislation and other mechanisms and strategies can be used to fully integrate the human rights model across the EU. One personal example of the persistence of the medical model she said, was that people sometimes approach her on the street as if she was ill, to which she responds that she is “quite well” and just happens to be a wheelchair user.

Ms Anca said: “I am not sick, we are not sick. We just have a disability.”

Ms Anca’s speech addressed a number of issues that affect persons with disabilities within the EU. Among the key points she highlighted were:

- The Convention is about promoting, protecting, and ensuring the full and equal enjoyment of all human rights for all people with a disability.
- Perceptions of the rights of persons with disabilities as limited to benefits and welfare issues should be challenged.
- A new disability agenda for 2020-2030 is an opportunity to be welcomed.
- The European Pillar of Social Rights could be broadened to address a wider range of issues affecting persons with disabilities.
- EU Structural Funds can be a tool for helping tackle ongoing barriers, including to freedom of movement and accessibility.

On the Convention **Ms Anca** said: “I think it is a very significant. It means we start the 21st century by talking about equal rights for people with disabilities. We can talk about it every day, every week, every year.”

Ms Cisternas Reyes was the next panelist. Speaking on behalf of the UN Committee on the Rights of Persons with Disabilities, her detailed presentation focused on the work of the Committee, general achievements since the adoption of the Convention, and the challenges remaining. She commented that following the UN

CRPD and the work of the Committee the UN General Assembly now looks at the issue of disability “from a different perspective.”

She provided a number of examples of positive developments, especially with regards to the connections being made between the rights of persons with disabilities, the CRPD and other UN Conventions, instruments and human rights committees, for example those focused on the rights of women and children and sustainable development. These developments have been important in moving towards the “mainstreaming” of rights for persons with disabilities at an institutional level but also across policy and society, she concluded.

Ms Cisternas Reyes said: “It is important that when there is an interface between committees and areas of work, that persons with disabilities [are] fully taken into account.”

Some of the items **Ms Cisternas Reyes** brought to the attention of delegates were:

- Evidence of progress within the UN includes that 15 UN General Assembly resolutions refer to persons with disabilities and four Optional Protocols have references to accessibility.
- There is a significant body of case law across the EU and internationally following the adoption of the UN CRPD, including relating to accessibility and access to justice.
- The EU’s commitment to the Convention is very significant, including through legislation.
- Promoting further ratification of the UN CRPD and additional protocols is vital.

Ms Cisternas Reyes concluded: “The rights of persons with disabilities is not an island. It is universal. And it should run through every system that deals with human rights.”

The moderator, **Ms Naughton**, rounded off the panel by stressing that there are big challenges within the EU such as the UK’s referendum to leave (Brexit), and that more governments are being elected in Member States “who don’t have full commitment to the international human rights framework”. In this context, engagement and political participation are more important than ever to defend human rights, she said. She also paid tribute to Sheena Walsh, a leading advocate with Down Syndrome Ireland who campaigned for the rights of persons² with disabilities and who recently passed away.

OPEN DEBATE 1

Comments from the floor and panel responses

Following the informative and detailed presentations from speakers on the opening panel there were a range of comments and questions from the floor. Members of the panel responded when required. The discussion centered on 2 broad themes: the impact of the Convention to date, and how to ensure that the rights of persons with disabilities are protected and enforced.

The impact of the UN CRPD to date: In the first instance, members of the audience including Cian O’Connor from Down Syndrome Ireland, were keen to acknowledge the importance of raising awareness and marking the 10th anniversary through the conference. On progress to date, Executive Director of the European Union of the Deaf, Mark Wheatley wanted to know Ms Cisternas Reyes’ thoughts now that the EU has “gone through the process of implementation” of the UN CRPD. Mr Wheatley wondered: “How are

we doing? Are we on our way to progress? What have you seen? And what are the ways to still improve?”

Another delegate, Rodrigo Lupo, this time from the Association Egalite des Chances, France, commented that even with the Convention in place and actions at a national level, it could be difficult to “achieve anything on the spot in daily life.” He was eager to learn about examples of where specific progress on improving the lives of people with disabilities had been made. There was also a statement made by Jorge Gouveia, from the Portuguese National Confederation of Organisations of Disabled People regarding the situation of the rights of persons with disabilities in that country. This included the role of NGO’s in promoting human rights since Portugal ratified the UN CRPD in 2009.

Ensuring the rights of persons with disabilities: Miro Griffiths, a researcher from Liverpool John Moore’s University in the UK who works closely with ENIL made a strong point about possible contraventions of the rights of persons with disabilities at a national level. He spoke about the recent UN investigation by the Committee on the Rights of Persons with Disabilities into the UK government. In its report published in November 2016, the Committee concluded there had been “grave or systematic violations” of the human rights of persons with disabilities as a result of government benefits and welfare reforms. “Subsequently, the UK government has dismissed the report and disregarded all the recommendations,” Mr Griffiths said. He asked if this would become a case study for how states respond to violations being declared.

Barbara Martin Munoz, Second Vice President of the European Blind Union enquired about the ratification of the Marrakech Treaty and what the UN Committee was recommending. The issue of rights in terms of access to transport and freedom of movement, a topic that would be the focus of a later panel, was raised briefly by some delegates. This included a contribution from David Adams from the European Guide Dog Federation who recounted how he was denied boarding on an aircraft, an incident which he says caused “distress and inconvenience.”

Responses from the panel on the impact of the UN CRPD included: Ms Cisternas Reyes addressed a number of the points raised by delegates. Regarding progress in the past 10 years she referred to legislation passed and mentioned that “harmonization” of laws on accessibility is important for the future. She remarked that there were complex issues to deal with such as legal capacity and deinstitutionalization but said there was a lot to be positive about. “EU Member States have taken a clear political decision and will to implement the recommendations from the Committee and that is a very positive aspect,” she told the conference.

Ms Cisternas Reyes added that when the EU completes a “follow-up procedure” to see “what has been done as regards to various recommendations...we will see a more concrete view of what has been achieved.

Ms Naughton added that EDF had recently published the first in a planned series of annual European Human Rights reports. These will assess the progress on “various aspects of CRPD” she said.

Responses from the panel on ensuring rights included: Ms Cisternas Reyes told the conference that with regards to the UK inquiry, an updated report would be out soon after the next Committee session. More generally, she added that as far as meeting standards goes: “public international law covers state responsibility,” and that achieving and implementing recommendations is “very important”. Ms Cisternas Reyes reminded delegates that the **Convention is “only 10 years old” and that the Monitoring Committee has been there for eight**. “You have to look at all which has been achieved,” she said. In terms of ratification of the Marrakech Treaty Ms Cisternas Reyes said the answer is “categorical” that the Treaty is ratified.

PANEL TWO – UN Convention and a Social Europe: Poverty, Social Protection and Employment

The members of this panel were: Emmanuelle Grange: Head of Disability and Inclusion Unit, Directorate General for Employment, Social Affairs and Inclusion, European Commission; Rodolfo Cattani: Secretary General of the European Disability Forum. The European Policy Framework and the CRPD; Esteban Tromel: Senior Disability Specialist, Conditions of Work and Equality Department, International Labour Organisation.

A Social Agenda – Addressing poverty, social exclusion and shaping future progress

Adding to the previous panel's discussion and debate, as the first speaker of panel two **Mr Cattani** opened by calling for a “new approach to disability policy-making” across the European Union in order to build upon the UN CRPD. He encouraged the EU and Member States to work even more closely in the coming years towards full implementation of the Convention with the “active involvement of persons with disabilities and their representative organisations.”

On behalf of EDF **Mr Cattani** told delegates: “We call for a more ambitious and holistic approach to the Convention, especially in those areas where discrimination and exclusion still exist.”

Mr Cattani dedicated time to talk specifically about the European Pillar of Social Rights, which he said was: “an important rights-based initiative”. He outlined a list of EDF recommendations for how it might be improved during the consultation period. These included that the Pillar have provisions for the monitoring its impact at the national level. **Mr Cattani** said EDF was recommending that the Pillar ensure “a social protection floor and a minimum income scheme” as an added protection for persons with disabilities against poverty and exclusion.

In addition, he said the scope of the Social Pillar should be widened to incorporate undocumented migrants and refugees, “in particular those with disabilities.” **Mr Cattani** also stressed that the three main categories in the field of employment and social policies within the preliminary outline of the Pillar, namely: equal opportunities and access to the labour market; fair working conditions; and adequate and sustainable social protection: “are important for persons with disabilities”. However, he added, the impact of inequality and poverty should not be underestimated.

Some of the other main points made in **Mr Cattani's** presentation were:

- The fallout from the 2007/2008 financial crisis has had enduring consequences for persons with and without disabilities. Among the ramifications has been rising inequality and social exclusion as well as a widening gap between rich and poor.
- Austerity and cuts to social programmes in many Member States have left millions of persons with disabilities worse off and this presents major challenges for the EU.
- The economic and social situation are challenging but the 10th anniversary of UN CRPD exemplifies the “extraordinary results” that the disability movement has achieved in Europe “thanks to this powerful instrument.”

Mr Cattani concluded: “We can be reasonably optimistic when looking at the future as we are stronger and more experienced, but also respected as serious and engaged counterparts. A new decade of hard work is ahead of us.”

Esteban Tromel has held many roles advocating for the rights of persons with disabilities but at this year's conference he was speaking in his capacity as an expert in employment rights. **Mr Tromel** provided a thorough overview of some of the most pertinent issues surrounding disability, employment and social protection globally.

He began with a brief review of the current employment situation in Europe referring to common barriers and inequities when compared with non-disabled people. These include lower tertiary education levels, higher unemployment rates and lower wages when actually in work. Mr Tromel referred also to “big gaps” in employment patterns between persons with moderate and more severe disabilities, and by gender.

Mr Tromel reminded attendees: “These different elements brought together make [people with disabilities] overrepresented among the population at risk of poverty and social exclusion.”

The Convention needs to be regarded as a central “lever” to full participation, **Mr Tromel** told delegates. In many parts of the world disability continues to be defined in terms of “work capacity” and this is a limiting and restrictive approach that needs to be challenged, he proposed.

Mr Tromel referred to some examples of the negative effects of this approach and how it can reinforce poverty and exclusion. In one country, he informed delegates, the social security system might provide intensive back-to-work help for someone who acquires a disability yet for someone born with a disability or who has never worked, no such intensive programmes are available.

Some of the topics referenced by **Mr Tromel** included:

- The UN CRPD has been a vital instrument across the world for advancing human rights, and within the EU it reinforced and built upon important existing rights.
- There has been a clear shift over the years, aided by the Convention and the international disability movement, to make training and employment issues mainstreamed.
- The 2030 agenda for sustainable development is important and “visibility” of persons with disabilities has been improved within this, thanks to advocacy efforts.
- There have been successes from the ILO's collaboration with private sector employers to improve work opportunities for persons with disabilities. The Global Business and Disability Network generated positive results through networking.
- Moving persons with disabilities from ‘informal’ to ‘formal’, paid employment is a key issue.
- Enhancing opportunities within mainstream vocational and youth training is crucial for equal rights and access to work.
- The diverse nature of the disabled workforce and wider shifts in the nature of employment, for example homeworking, need greater attention.
- Exploring an effective response to rising levels of anxiety and depression as a result of labour market changes, uncertainty, and insecure employment is required.

Mr Tromel said: “What [the] Convention reminds us from the point of view of employment is the interrelatedness of all rights.”



OPEN DEBATE 2

Comments from the floor and panel responses

Following the second panel of the day 3 broad themes emerged from the comments and questions. This was an extensive discussion session about complex issues. The themes encompassed: full inclusion in the workforce, rights and the purpose of social protection now and in the future, and the role of the European Pillar of Social Rights.

Full inclusion in the workplace: A number of points were put to the panel on this topic. The first remarks came from Markku Jokinen, President of the European Union of the Deaf. Mr Jokinen wondered what should be the priority to obtain full inclusion in workplaces. He asked: Is it the accessibility first? Or do you change social protection and reasonable accommodation? “The inclusion of persons with disabilities needs to be preempted by a more welcoming environment,” Mr Jokinen added. Deaf people had to break down numerous barriers, he pointed out, for example bringing interpreters into meetings. He stressed that this was not the same as full participation if compared to environments where deaf people could work “totally in sign language”.

Other questions and comments addressed ongoing barriers in the way of finding employment. One attendee, Barbara Verna from the [European Deaf Blind Union](#), told the conference of personal difficulties she and people she knew who were deaf blind had experienced trying to find employment. According to Ms Verna her experience of applying for work involved receiving only “bad offers”. Employers are still likely to see disability in terms of the medical model, she added. Ms Verna suggested employers should be given more information in order to make decisions that benefit persons with disabilities seeking work.

Sanja Tarczay, President of the European Deaf Blind Union commented that people who are blind and deaf are “the most excluded group”. She spoke of how as a young woman of 25 who was highly qualified she was dismissed as not able to work. “I was shocked,” she told fellow delegates. “I said: ‘I can contribute a lot.’ They said: ‘No. You are already retired.’” Ms Tarczay wondered what kinds of funds might be available to facilitate employment of deaf blind people.

Magdi BIRTHA from COFACE – Families Europe raised the issue of the impact of gender and caring responsibilities on accessing work and how this was another significant hurdle for people, particularly women with disabilities.

Rights and the purpose of social protection: Some very detailed comments and questions were put to the panel on this subject, many of which overlapped with other, related issues including employment. Mr Cattani made a statement saying that social protection is “still fundamental” and he stressed the importance of a rights-based approach in order to shield persons with disabilities from exclusion and discrimination. “I’m not referring to abstract rights. I’m talking about the right to eat food, right to heating,” he said. “These are all universal rights. We need of course to concentrate on the more serious problems, such as the impoverishment of the population; the exclusion of a large part of it.”

Mr Vardakastanis suggested that activists who argue that there is no need for social protection are wrong. “It is easier for us in the disability movement to speak about equality and non-discrimination, even equal recognition before the law, than to discuss employment, labour market issues, social protection,” Mr Vardakastanis told delegates.

Albert Prevos, from the French Council of Disabled People wanted to know what Mr Tromel’s view was on the idea of a Universal Basic Income, which is being promoted by some organisations in France and elsewhere. In addition, he asked about the suggestion by some of a “universal social benefit” and what this might involve.

Linking the themes of social protection, benefits systems, and access to work, Rodrigo Lupo of the Association Egalite des Chances, France said that while in some instances there are welfare benefits aimed at helping people into work, some systems are changing in ways that are negative. For example, the removal of benefits after a disabled person works more than a certain number of hours a week.

The European Pillar of Social Rights: Reflecting the fact that the Pillar of Social rights featured throughout the conference, there were some comments on its role and development. One of these came from Giampiero Griffo from the Italian Disability Forum who referred to the Pillar as “based on the concept of protection for the vulnerable. And it has to do with discrimination, particularly during periods of crisis such as this one.” **Mr Vardakastanis** said the Pillar was “not going to bring about new rights”. Rather, he said: “It is a proposal on how to implement, how to organize labor and social protection policies.” He said that there was no mention within the Pillar of the UN CRPD or the 2030 Agenda.

Magdi BIRTHA from COFACE – Families Europe said it was difficult to see how the Pillar would help people, not who had lost jobs, but who were out of the labour market entirely and were marginalised, including many persons with disabilities but also other groups such as the homeless.

Responses from the panel on full inclusion in the workforce included: Replying to Mr Jokinen, Mr Tromel said that policy makers could answer some of the points he had raised but that when it came to the ILO, their work with the private sector was to look for companies that have “strongly embraced diversity” in an effort to persuade other firms to do the same. Mr Tromel mentioned a new guide to reasonable adjustments for employers that his organization was launching the same week as the conference. Employers needed more guidance on what disability means he said, but he added that making a strong case for employers to be proactive with diversity, including different disabilities, was essential.

One of the big problems with inclusion for some disabilities is funding, Mr Tromel said. If a second person such as an interpreter is required an employer may not have a budget for that, he pointed out. The

example of interpreters for deaf people “is a clear example of the interaction between social protection and employment.” Mr Tromel noted.

Other replies on inclusion at work were offered by Ms Grange who, responding to the comments from a delegate on gender and caring excluding people from the workplace, said these are issues the Commission is aware of and were on the agenda in work-life balance in the Commission. Ms Grange stressed that employment was a top priority for the Commission, including through funds. She added that progress on employment was key to the wider goals on implementing the Convention and “for changing your lives”. Ms Grange also commented that delegate’s personal reflections on their negative experiences of trying to find employment were “unfortunately” right for many people, adding that there “is still a lot to be done.”

Responses from the panel on rights and the purpose of social protection included:

Regarding social protection issues and the point raised about universal income and benefits, Mr Tromel offered a number of thoughts. He said he believed advocates who suggested that the UN CRPD should not have had an article on social protection are wrong. He said while he understood their concerns he referred to some Member States, where the “umbrella” of disability legislation and the wider approach was one of “old-fashioned” social protection. One of the biggest challenges for the future, he said, was to design a system that “promotes participation” in the labour market and “not dependency.”

He added that he had not studied in detail the issue of universal income but commented that any consideration of it should involve a division of the costs for persons with disabilities and those without.

Responses concerning the European Pillar of Social Rights: After listening to comments made about the Pillar, Ms Grange responded by saying the consultation process was important for making sure the voices of persons with disabilities and DPO’s were heard and taken into account. She said their contributions had made a significant impact and that she hoped there would be further exchanges ahead to make even more improvements: “With all the contributions that civil society put forward.”

At the end of the panel, **Raymond Ceccotto** from ARFIE (Association for Research and Training on Integration in Europe) made a short statement introducing a project called ‘FORZA – training towards active citizenship’ that ARFIE and 8 other organizations from 7 different countries developed over the years 2013-2015. **Mr Ceccotto** explained that the project aimed at enhancing active participation of persons with intellectual disabilities and allowed them to learn more about their rights and obligations as citizens.

“We were able to have an exchange of practice on accessing rights and exercising rights. Particularly when it comes to active participation and citizenship,” Mr Ceccotto told delegates. **He added that the success of this international initiative can serve as “an example of good practice for participation of persons with disabilities in terms of the UN Convention”.**

DAY ONE – Afternoon

Following the morning's engaging presentations and discussions, the second half of the day began with the Access City Award 2017 ceremony during which **Commissioner for Employment, Social Affairs, Skills and Labour Mobility, Marianne Thyssen**, reflected on many of the central themes of the conference. She spoke of how the celebration was not one of institutions or of politicians "but about people and their rights". **Commissioner Thyssen** reminded delegates of the hard work, campaigning, and awareness raising that went in to securing the Convention in the first place. She reiterated too that the UN CRPD was not only a consolidation of a shift in the way disability is perceived, but a commitment by the EU and others to "make this shift a reality on the ground".

Actions by the European Parliament and the Economic and Social Committee to evaluate the EU's progress on the implementation of the Convention have also been important contributions to the European Disability Strategy as it is being finalized, **the Commissioner** said. She stressed also the challenges remaining, many of which have been highlighted during consultation with DPO's, including lack of equal opportunities in the workplace, and barriers to independent living and full accessibility. Input into the development of the Pillar of Social Rights was vitally important she added, especially bearing in mind the "increased pressure" on persons with disabilities from the financial crisis and more broadly, a rapidly changing labour market.

Commissioner Thyssen told the conference: "It is only together that we can make sure that all levels of government, all businesses and citizens are driven by the principles and rights of the UN Convention, within the EU and beyond."

PANEL THREE – Accessibility and Freedom of Movement Within the EU

The members of this panel were: *Inmaculada Placencia Porrero: Senior Expert on Social Affairs, Disability and Inclusion Unit, Directorate General for Employment, Social Affairs and Inclusion, European Commission and panel moderator; Ask Lovbjerg Abildgaard: Member of the Executive Committee of the Danish Association of the Blind; Ruth Lopian: Policy Officer, Social Aspects and Passenger Rights Unit, Directorate General for Mobility and Transport, European Commission; Petra Tiihonen: Project Manager of the EU Disability Card Project in Finland.*

Making a Change – Celebrating achievements and building on existing rights

Introducing the final panel of Day One moderator, **Ms Placencia Porrero** explained to attendees that choosing exactly which topics to highlight in relation to accessibility and freedom of movement was not an easy task. Nevertheless, she said, acknowledging achievements so far and exploring ways to improve further, was key. Picking up where **Ms Placencia Porrero** left off, longtime disability rights advocate **Ask Lovbjerg Abildgaard**, who is blind, set the tone for the session when he stated that accessibility is a fundamental human right. **Mr Abildgaard's** talk spanned numerous aspects of accessibility, including its role in enabling the enjoyment of other rights such as to employment and education. He also stressed that freedom of movement reinforces accessibility – and vice versa.

Mr Abildgaard told delegates: "To be able to access facilities, information, transport etc., on equal terms with other people is a right in itself for persons with disabilities."

The focus of the presentation was on “five freedoms”. These were defined by **Mr Abildgaard** as: accessibility and the free movement of people, goods, services and capital, but also knowledge and information. Explaining the five freedoms, along with associated challenges and opportunities, **Mr Abildgaard’s** remarks included the following:

- When it comes to the free movement of goods the European Accessibility Act has been a step in the right direction, yet more needs to be done. Standardization of goods and services is essential for persons with disabilities so that “if we buy a product in another EU country that will comply with the same standards that we have in our country.”
- The growth of the service sector means it is vital to push for accessibility in this area, including disability awareness training for service staff.
- Progress on the free movement of people in the EU has been significant with laws and initiatives improving passenger rights across modes of transport. European regulation can have a significant role to play in this. However, much more needs to be done across transport networks including in terminals. “If part of the chain is not accessible, then we risk the whole trip being inaccessible.”
- Capital investment in accessibility and related products should be widely encouraged including at a EU level for research into potential new solutions.
- Equal access to information and technology is increasing in importance. Improvements around access to websites are to be welcomed but this needs to be broadened, for example to fully include media content and educational platforms.

Mr Abildgaard concluded: “We need to map the existing accessibility barriers and try to address them with legislation and standardization.”

In her presentation **Ruth Lopian** reflected many of Mr Abildgaard’s sentiments on the central role of freedom of movement and accessibility in enhancing the fundamental rights of persons with disabilities. She provided an overview of existing passenger rights, including the key achievements in the legal and regulatory frameworks.



In the first instance **Ms Lopian** highlighted key developments for ensuring accessibility and freedom of movement through a rights based approach to disability. She reported that the major developments included the UN CRPD's Articles 9 and 20, the 2011 White Paper on Transport, and the European Accessibility Act, which includes a set of standards for accessible transport and infrastructure. After talking through important legal frameworks and regulations she stressed the primary objectives and scope of passenger rights legislation.

Ms Lopian told delegates: "When we look at the scope and objective of passenger rights legislation, the main objective is to protect persons with disabilities."

Among **Ms Lopian's** extensive observations and comments were the following:

- Transport assistance must be provided in a "professional and seamless" manner so that persons with disabilities have access "on the same footing" as non-disabled people. That includes at no additional charge and that it is tailored to individual needs and disabilities.
- Many people continue to encounter difficulties with access and assistance while travelling. For example, when flying, pre-notification of needs can determine whether the assistance provided is suitable.
- As well as laws and regulations, staff training is critical.
- Transport operators must make access conditions publically available. Information on conditions of carriage and journey conditions should be available in appropriate, accessible formats, "so all persons are aware of what they expect."
- Mobility equipment is vitally important, especially in air travel. Carrier liability for loss or damage, complaints procedures and compensation mechanisms exist under passenger rights legislation and regulations, however more improvements are necessary.
- The Commission has plans in place to address many of the ongoing difficulties relating to travel. These include revisions to air and rail passenger rights regulations and on introducing disability awareness training and promoting good practice to operators.

Speaking about the Commission's work and achievements to date on passenger rights **Ms Lopian said**: "We are not stopping there."

When asked about the launch of an EU Disability Card, people surveyed in Finland had a range of reactions. According to **Petra Tiihonen**, project Manager of the pilot EU Disability Card Project in Finland, who addressed the conference as the final speaker of the first day, a typical example was: "I often have to explain that I really do have a disability, because it's not visible." Another was: "I could prove that I need a seat in the front, because I can't see from anywhere else."

Finland is one of 8 Member States currently participating in the pilot project. The goal is to bring the EU Disability Card in to practice across the participating countries on a voluntary basis. This Commission initiative launched in February 2016, aims at helping persons with disabilities travel more easily between EU countries, by developing a system of mutual recognition.

Ms Tiihonen explained that the EU Disability Card, which has the aim of ensuring an equal access to certain specific benefits – primarily in the areas of transport, culture, leisure and sport – is another potential

mechanism for promoting a rights-based approach to disability across the EU.

Reflecting on how the card might work **Ms Tiisonen** told delegates: “*Its all about cooperation.*”

Ms Tiisonen gave a summary of the work being done to develop the card in Finland. Points she made during her presentation included:

- The card is being developed through government bodies, persons with disabilities across society, DPOs and key local organisations like service providers working together.
- Currently Finland is at the stage of finalizing the criteria for the card. Three key questions during this process have been: Who will get the card? How will people get the card? What do you get by having the card?
- Other key stages and activities include: creating a system to issue the card, raising awareness, establishing a ‘national package of advantages’ with service providers and the direct input of persons with disabilities, creating a fully accessible website, and organizing publicity campaigns.
- Results are expected to be on an individual, local, national and EU level. Overall the card should enhance rights through improved accessibility and freedom of movement. It is also expected to raise awareness of the UN CRPD.
- It is anticipated that the scheme in Finland will be modified over time following feedback.

Ms Tiisonen said: “*One principle that we have chosen is that even though we are not finished yet, we are open, active. And the communication is accessible throughout the project.*”

Following **Ms Tiisonen’s** presentation, conference delegates were shown a short video that explained the origins and purpose of the Disability Card and how it is being rolled out in [Slovenia](#).

OPEN DEBATE 3

Comments from the floor and panel responses

The final panel of day one produced a vigorous and extensive discussion of the issues. Panel members responded as required. The session was dominated by 3 themes with questions and observations regarding the EU Disability Card, accessibility on different types of transport, and the topic of wider accessibility and rights.

Freedom of movement and the EU Disability Card: Reflecting an enthusiastic interest in the EU Disability Card there was a wide range of comments. Teresa Amat from the European Association of Cochlear Implant Users wished to know more about the design of the card remarking that its current design resembled an EU “medical-type” card. “We would like to move away from that model,” she said. Alba Gonzalez from CBM International began her point by saying that the card was a welcome development, but commented that it “focused on how to support persons with disabilities when travelling abroad,” rather than someone staying for a longer period. She also said there could be difficulties too when someone requires a personal assistant to travel with him but the card applies only to the person with a disability.

Mark Wheatley, Executive Director of the European Union of the Deaf added his thoughts too. He said the card was “very important” but that he wanted to make a point of clarification. When first announced, it was stated that the card would “give the right to sign language interpretation” he said. However, it appears that

this was only in places, such as museums, where interpretation services were already in place and he asked for clarification on this point.

Making different modes of transport accessible: The numerous questions and comments regarding accessible transport and freedom of movement included some about the rights and experiences of deaf people, blind and partially sighted people, individuals with sensory disabilities, and those with intellectual impairments within air travel in particular. One delegate asked about the precise rights of deaf people wishing to travel by plane and Barbara Verna from the European Deaf Blind Union stressed that there should be better training for airport staff on different disabilities if needs were to be met. She also had questions regarding differences between airlines in how many people with a disability they permitted to travel together.

Judith Jones, Executive Director of the European Guide Dog Federation told the conference of frustrating experiences traveling with a guide dog. For example, being told to muzzle the dog or that only one dog could be on a flight at a time. Sometimes, she said, airlines even asked for proof the dog was trained. One delegate said there was a need to consider the issues of rights when travelling in urban areas and where “the chain” of travel included more than a single mode of transport. Veronique Duchenne from the [Belgian Disability Forum](#) had a question about pre-notification of needs to transport companies and if there were plans to reduce the time for advance notice.

Moving towards accessibility for all: Reflecting some of the comments made about accessible transport, Pietro Cirrincione, vice-President of [Autism-Europe](#) broadened the discussion with comments about accessibility issues for persons with disabilities beyond those related to mobility. “Ten years after the Convention, the accessibility needs of other types of disabilities are still poorly understood,” he told delegates.

For people with communication difficulties or who have problems with social interaction, he added, information should be provided in pictures and symbols form, easy to read text and other processes in place to guard against “sensory overload”. Staff should be better trained in public services to understand the full range of disabilities, he said.

Vidan Dankovic from the Accessibility Audit Association, Serbia made a number of points including on legislation that promotes accessibility and emphasized that it should be made easier for people to report when legislation or standards are not applied. He suggested making reporting mechanisms digital, for example to highlight an inaccessible website, but also for other infringements. “Simply in order to actually document some of the problems and also be able to give priority to the issues that are most reported on,” he said.

Responses from the panel on the EU Disability Card included: Answering the question about design of the card Ms Tiihonen mentioned that the choice of blue was to emphasize the colours of the EU. Ms Placencia Porrero commented that the card had a braille sign which the health card does not, adding that a familiar design may help with “mutual recognition”.

Addressing the topic of personal assistants and travelling within countries in her response, Ms Tiihonen said a “key issue” for many people was not having a “tool” to prove the status of their personal assistant and in many cases having to pay for two people “even on public transportation.” During the development of the card in Finland, she said, discussions had taken place about possibly placing an ‘A’ for assistant on the card where required.

Ms Placencia Porrero said the Commission “understands the concerns and difficulties” being raised but that the hope was that as the scheme evolves, Member States would increase the benefits they attached

to their cards. Ms Tiihonen confirmed that at this point the card does not automatically give a right to sign language interpretation.

Responses from the panel on making different modes of transport accessible included:

Some very detailed replies were given on the topic of transport and first among these came from Ms Lopian regarding air passenger rights, including for groups travelling. She told the conference that in the absence of Europe-wide safety rules for aircraft, pre-notification of needs is very important. In terms of information provided on aircraft Ms Lopian said this was an issue that may be addressed by the guidance document currently being worked on by the Commission. It was possible, she said, that “some recommendations on the number of persons with disabilities,” could be included. She mentioned also the regulation around training airline and airport staff on disability rights issues and said there has to be awareness that covers “all types of disabilities.”

Ms Lopian said it was important for people to complain directly to companies and to national enforcement bodies following a bad experience, for example being denied access with a guide dog. She remarked also that she wished to hear when persons with disabilities had positive experiences and called on delegates to come forward with reports of good practices.

On the issue of pre-notification of needs Ms Lopian commented that the time frame for pre-notification differed between countries. She said the Commission would look into the issue. For shorter trips or at short notice she pointed out that for rail travel, for example, it is expected that assistance will be provided: “But it only has to make reasonable efforts.” Ms Placencia Porrero also commented. She said the goal of improving wider accessibility is directly linked. **“The more accessibility that you have, the less special service you need.”**

Additional responses about freedom of movement and transport came from Mr Abildgaard and were related to urban transit and using multiple modes of transport during travel. Mr Abildgaard said that the difficulties experienced changing transport mode was “a strong argument” for going further than the proposed EU regulation. “If the transport chain is to be fully accessible, then we also need the local link to be included.” He suggested this might be something to be incorporated into the European Accessibility Act. Ms Lopian said she agreed with Mr Abildgaard on the importance of “seamless assistance” between different transport modes. She added that the Commission was also “looking into the rights of persons with disabilities in the urban environment.”

Responses from the panel on moving towards accessibility for all included: Mr Abildgaard responded to comments regarding the ongoing need to widen the understanding of disability accessibility to encompass all disabilities by first saying that policy makers and the disability community could do much more. “I don’t think we have been inclusive enough in terms of linking [the] accessibility concept to also encompass cognitive and intellectual disabilities,” he explained to the conference. He said there has been progress, for example on accessible websites, but that there was some way to go. Ms Tiihonen noted that this highlighted the importance of involving all the relevant stakeholders and persons with various disabilities in developing the EU Disability Card to make sure it worked for all.

Ms Placencia Porrero agreed and encouraged DPO’s to get directly involved in discussions around standardization because this is where technical standards are set. “You have the right to be there. So, please, go to your national delegations.” On the topic of monitoring with standards said “more and more” were being accompanied by tests to measure compliance. She gave the [Web Accessibility Initiative](#) as one example. She noted that at times there was a “tension” between setting “precise and prescriptive” standards to make it easier to monitor and being general enough to encourage creativity and innovation. “Finding the right balance is what we constantly try to do when we develop standards and legislation,” she concluded.

2017 Access City Award Ceremony

29 November 2016

#EUDisability

#EUAccessCity

#EDPD2016



DAY 2



Thank you very much. See you
(applause)
(Music of James Bond)



DAY TWO

Day two of the conference proved to be as stimulating and thought-provoking as day one with a schedule full of interesting contributors. Opening the proceedings was 19-year-old **Beatrice Maria Vio**, also known as ‘**Bebe**’, who shared her remarkable personal journey. The young fencer had her limbs amputated following severe meningitis yet went on to be a world champion wheelchair fencer and Paralympic gold medal winner representing her native Italy in Rio in 2016. She made a profound impression on the audience. “I began fencing when I was five,” **Bebe** told delegates. “In spite of the disease from which I suffered, which caused me problems with my legs and arms. Obviously, I wanted to get back to sports. Particularly fencing.”

Bebe spoke about the importance of friends in her life and of helping to encourage others to take part in sport and she talked too of how she hoped that sharing her own experiences might help others. She said she considers herself “lucky” and is a passionate advocate for sports, especially among young persons with disabilities. It may be easier for some than others, she said, but this should not discourage people from having access to and participating in sports.

Bebe concluded: “Sport is particularly important. It is a way of improving life. And we should get more people to do it. Because it can be done by the disabled as well as anybody else.”

PANEL FOUR – THE RIGHT TO INDEPENDENT LIVING

The members of this panel were: ***Stig Langvad:** Independent Expert Member of the UN CRPD Committee and Rapporteur on the upcoming General Comment on Independent Living and moderator of the panel; **Kapka Panayatova:** European Network on Independent Living (ENIL) representative; **Rosita Hickey:** Head of the Strategic Inquiries Unit, European Ombudsman.*

Making independent living and full inclusion a reality

Introducing the opening panel for the morning and speaking in a personal capacity the moderator **Stig Langvad** emphasized the importance of Article 19 of the UN CRPD “because it is about living independently in your community.” **Mr Langvad** said he had come to think of the Article as especially significant because it is impossible to live independently if accessibility is denied or is restricted. **Mr Langvad**, who told delegates of how he had experience of living in an institution, spoke also about inclusion. “Inclusion means that we must mainstream disability into all spheres of society,” he said. Fundamental to this was “liberating” people from institutions, he underlined. The right to self-determination and personal autonomy is fundamental **Mr Langvad** added. He also stressed the importance of persons with disabilities “being visible” within communities.

Mr Langvad said: “It is not just about being visible. It is also about being able to act together; to do things together. You have to break down the invisible shields that are keeping people away from each other.”

Kapka Panayatova from the European Network of Independent Living began her talk with a call for a minute’s silence in tribute to individuals who had been key figures in the fight for independent living but who had died in the past few months. These were Martin Naughton from Ireland, Peter Lambreghts from Belgium and Debbie Joly from England. In what would turn out to be a typically passionate speech on the second day of the conference **Ms Panayatova** offered an appraisal of the UN CRPD as “a remarkable achievement” confirming a “paradigm shift” in the perception of disability.

Ms Panayatova said the UN CRPD was the first time in history that a global political document: “distinguishes between impairment as a health condition and disability as a social status.”

Against this backdrop **Ms Panayotova** made a number of pertinent observations on the status of persons with disabilities generally, the work of ENIL, and on various important issues surrounding independent living. These included examples of positive changes as well as remaining barriers.

Among **Ms Panayotova's** main points were:

- ENIL has worked for two decades for policies that promote full inclusion and living independently in the community with appropriate support and access to services.
- 10 years after the UN CRPD many countries still operate a medical model of disability and this limits the scope of social inclusion to policies focused on health and welfare provision. This perpetuates isolation and relegates many people to institutional facilities.
- In some countries, many people are denied legal capacity, especially those with intellectual disabilities.
- Deinstitutionalization has been in progress for years but the process is far from complete.
- There are marked variations across the EU in terms of support. For example, in the UK the threat of re-institutionalization has emerged because provision of support is being based on essential health and social care needs, not on the “aspirations” of individuals.

In addition, **Ms Panayotova** pointed out that the concept of personal assistance has not been mainstreamed across Europe, especially for people with extensive or complex needs. In too many instances she added, services that should be accessible to all, including education and employment, are relegated to segregated facilities such as day care centres. The conference is a “fantastic” forum **Ms Panayotova** added but she stressed that it should also be a priority for persons with disabilities to be directly involved in forums and debates beyond disability.

Ms Panayotova said: “There is still plenty to be done in order for disabled people to access Independent Living.”



Next, delegates heard **Rosita Hickey**, head of strategic inquiries at the European Ombudsman's office, outline the role and responsibilities of the Ombudsman as well as work that has been done specifically affecting independent living. The presentation began with **Ms Hickey** explaining that as an organization that responds primarily to complaints, it is vital that complaints are expressed, recorded, and acted upon.

Some of the issues brought to the attention of delegates by **Ms Hickey** were:

- If a lot of complaints are made about a particular subject the Ombudsman has powers to open an inquiry but the office always tries to be aware of wider concerns and issues.
- The office of the Ombudsman is limited to dealing with complaints about EU institutions, not those made within the Member States. "We can only do something if there is a failing at the EU level."

Ms Hickey also informed delegates of a recent inquiry by the Ombudsman on EU Cohesion Policy. As part of the process, organisations including DPO's were consulted. One striking outcome of this was the number of people who raised institutionalization as a primary concern, she said. A significant piece of feedback from ENIL and others was worries that funding through EU Structural Funds was being used to "maintain or extend the institutionalization of persons with disabilities". However, **Ms Hickey** reported: "significant changes introduced to the provisions governing use of Structural Funds 2014-2020" had gone some way towards addressing such concerns, according to organisations who responded the Ombudsman's enquiry.

Ms Hickey also reminded delegates that the Ombudsman's decision was published in May 2015. With the Commission responding to the 8 proposals of the decision in November that year.

Ms Hickey said: "A new framework was put in place for 2014-2020. And things are good. Changes have been implemented. We are in a much better situation."

OPEN DEBATE 4

Comments from the floor and panel responses

The panel on independent living prompted some very compelling discussions in the limited time available. Most of the debate centred on **2 themes**. These were the role of persons with disabilities in shaping the agenda and the discourse on independent living, with some discussion also about the European Ombudsman's main functions. Panelists responded as necessary.

Shaping the independent living agenda included: Most of the discussion following panel four was taken up with this topic. The debate was energetic with lots of suggestions being made for how to eliminate institutionalization and ensure genuine independent living and full inclusion. A number of delegates stated that there were concerns that the term 'independent living', and other words associated with inclusion, had been "hijacked" within some States to justify actions and policies that were actually contrary to the goals of living fully independent lives.

The role of Structural Funds came up a number of times. Mr Langvad said some applications for funds had been suspended due to complaints that they were not in line with deinstitutionalization. Merlin Kizant from Estonia and member of the IF Youth Group made two suggestions for changes to Structural Fund regulations. One of these was "concrete tests" to clearly differentiate between community living and institutional living. It was also proposed that an independent body within each country could be established

to monitor the use of Structural Funds money. Also related to this issue, Marie-Anne Paraskevas from the European Commission, DG Employment, Social Affairs and Inclusion (unit F1 responsible for the ESF and FEAD) said a lot of work was being carried out on how funds were allocated, including with the Expert Group on Deinstitutionalization, seminars in Member States and training for policy units.

Milan Sverepa, Executive Director of [Inclusion Europe](#) said not enough was being done to ensure the input of persons with intellectual disabilities into plans for investment and other aspects related to independent living. He said this means “not supporting fully independent living and carrying out their rights.” The same person said there was not enough attention being paid to people in institutions “and the violence they experience there.”

Rita Donabauer from the Austrian National Council of Disabled People made a comment that disability policy is “a horizontal” issue, not an isolated one. Because of this, she said, persons with disabilities should be involved in the wider drafting of legislation. She added that events such as the conference should have representatives from other areas of policy responsibility beyond disability so that the discussion can be broader.

The role of the European Ombudsman: Mr Langvad spoke briefly on this issue. He said he had concerns about what he called a “complaint driven” system and added that he believed the Ombudsman and the EU could do better.

Responses on shaping the independent living agenda included: The suggestion that language related to independent living had been appropriated by people who were not advocates of full inclusion was addressed by Ms Panayatova. She agreed that it had been hijacked but said there were a number of things that could be done. First, she said people should share the precise definitions ENIL has developed so that terms are clearly understood. Ms Panayatova also stressed the importance of “solidarity” within the disability rights movement to promote independent living for all. European Institutions were “crucial” to making progress she concluded.

Another vital step forward would be to make sure that persons with disabilities are in attendance at events and in discussions across policy areas. “Important areas of public life which are not directly named to be disability related,” Ms Panayatova explained. “We are not invited there.”

In terms of influencing the discourse and policy Ms Hickey said that in her experience, the “most compelling arguments” and input on the issue of deinstitutionalization and independent living come directly from those affected. “Those personal stories are convincing.”

Ms Panayatova agreed saying that she and many others in ENIL and beyond have been “repeatedly shouting” about key aspects of the struggle for independent living. This included that deinstitutionalization “is not about closing institutions” but being aware that big institutions are often replaced with smaller ones, rather than independent living in communities. “And everybody knows what should happen,” she said. “It is about the environment, provision of housing, personal assistance.”

With regards to Structural Funds, Ms Hickey mentioned that there was an expert group set up by Commission “specifically” on this topic. “That fed into the whole framework for setting up the new structure for implementing structural funds from 2014-2020,” she said.

Responses on the role of the European Ombudsman included: Ms Hickey was keen to reiterate that the office of the Ombudsman had a role both to respond to complaints – she called this “intelligence

gathering” – and to be proactive whenever possible. “It is important to avoid any sense the message I’m trying to convey, that in the EU institutions we sit and wait for complaints to come in,” Ms Hickey said. She added that the office does its best to collect relevant information beyond complaints but that it is very important that the body hears about specific grievances.

STORYTELLING & ANIMATION SEGMENT

Prior to the final panel of the conference, participants were addressed once again by facilitator, **Stien Michiels**. With her was animator **Muriel Orange** and together they presented, through storytelling and art, some of the ideas and thoughts conference goers had passed on to them over the two days. **Ms Michiels** put the feedback into verbal story form while **Ms Orange** painted an artist’s impression on a canvas behind her. Using a stream and a river as metaphors, the audience listened to a story of hope based on overcoming obstacles and barriers. Harnessing terms that were themes of the conference such as accessibility and inclusion, **Ms Michiels** reflected the ongoing struggle for the rights of persons with disabilities in her story.

She said: “We do not need heroes, we need ideas. Together we are stronger.”



Muriel Orange

This is a story

a story about a little stream, a main stream and a wide open sea.
a story of a past, a present and a future.
a story with an open mind, an open heart and an open ending...

There is gentleness in this story
and there is pride and fierce resolve.
There is disbelief
and the energy to achieve,
there is feeling small
and walking tall,
whatever happens
moving on...
There is the voice of reality,
and a whisper of magic,
and there is Love.
Yes, Love
and Hope.
No, no, not the kind of love and hope
that hushes you to sleep
without giving it a second thought,
but the kind that wakes you up
to create even more
of what is needed to go on.

To be honest, we are not sure if the story ends well.
As we all know: some stories do, some stories don't.
However, the most important thing about this story
is that it is told.

So, without further ado
this is how it goes...

Once upon a time
there was a little stream
that dreamt of finding a way to join
the largest river of its time,
the big big big Main Stream.
It wanted to immerse in its waters,
to change its course,
to flow together to the river mouth
and add all of its beauty
to the sea.

This little stream was particularly beautiful
and as diverse as the many drops in its bedding.
It was as silent as it was vibrant,
it was as slow as it was fast,
it was as colorful as it was silver white,
it shone as much in the light as in the dark.
The little stream did not judge

any of its appearances,
it enjoyed life
and saw the wonder of it all.
Life for the little stream was not always easy though.
It happened to live in a world where the big Main Stream governed land and laws.
A world where little streams were often disregarded, discriminated, belittled..
A place full of barriers not always easy for the little stream to travel through.
The little stream longed for respect and dignity,
empathy and understanding,
freedom and connection.
“Why can’t the Main Stream see the richness I can bring to the river and to the sea?
Why does it stop me from flowing to places
where I could bring all of my sparkles, my drops,
my splashing, my murmuring,
my fluidity, my stuttering,
my ups, my downs
and my endless wisdom of how to navigate it all?
It is unfair.
It is my right to be part of the whole.
I am as much water as the Main Stream is.
There is no reason for me to withhold.
I should fight for my rights,
fight for what is right!”

So came the day that the little stream
did not want to be silent any more.
It decided to build a boat.
In all its wisdom it knew
it couldn’t do this alone,
so it called upon the winds and the woods,
the moon and the sun,
it tickled the sky
and woke up the earth,
it swayed and swell
and spoke of its dream,
until enough of them took note
and did their part.

With the help of all these forces,
sooner than later the boat was built
and travel began.
1 year, 2 years, 10 years went by,
up stream, down stream,
on the boat went,
sometimes getting stuck,
sometimes going slow,
sometimes flying swiftly around the bend,
but always carried by the power of a dream:
the little streams wish to let its drops flow
in sync with it all.

As the boat travelled and travelled and travelled,
through landscapes never seen before,
remarkable things started to occur.
The boat became bigger and stronger,

more colorful and bright,
even at night a shining light.
Also the little stream grew
in beauty and strength,
meandering steadily for days on end.
And the sun and the moon,
the sky and the earth,
the winds and the woods,
they watched them go and smiled upon them :
we are your allies, they whispered,
please go on!

Finally the boat and the little stream
– not so little anymore –
reached the place
they were hoping for :

a huge huge gate
with a huge huge sign.
Main Stream, it said, Accessible for all.

The little stream and the boat sat for a while
watching the gate
and the boats passing by.
“How strange” said the little stream,
after some time went by,
“No matter how big I became and how hard I try,
I can’t seem to fully enter the waters behind.
The sign on the gate must be a lie,
I can only flow through
a few drops at a time...”

Suddenly the voice of the Main Stream roared:

Little stream.
There you are.
What is going on?
I saw your boat,
I heard your call,
I recommended a law,
made a new vow,
and created this sign,
accessible for all.
Is that not what you have been asking for?

Little stream sighed.
“Main Stream, it is a start,
and it brought us here,
at least we talk.
But please do understand:
words alone are not enough.
How can I add my beauty to the sea,
if you only accept a drop or two,
if I can not be fully part of you?”

Main Stream groaned...

"It is hard to change the course of an old river like me...
It is the past that flows through me,
in many different ways telling me
where to go and what to be.
What lays ahead I can hardly see,
and there you are, little stream
telling me about the sea.
But go on, what do you need from me?"

The little stream took a deep breath and said:
"I want to stream into you,
all of me
every difference, every inch of my quality
I need your hospitality."

As the little stream spoke,
the boat started waving its colorful flags,
and tens of drops popped up out of the stream
all of them adding a different voice:

- We need to turn hope into action
- We do not need heroes, we need ideas
- Let us put our ego to the side
- Together we are stronger
- Unity is our strength
- Let us co-construct
- Side by side
- in all our diversity
- still equals alike
- connected in a web
- here and beyond
- in every city
- in every theatre
- in every company
- in every town
- we are more than just a drop
- we are business
- we are politics
- we should constantly be on your mind

Even more drops joined the choir:

- Let us be creative
- And think before we build
- Help us understand
- Where to go, what to do
- in everyday life
- and in case of emergency
- If we can land on the moon
- then we can also do this
- Do not use force
- Listen to us
- Even if this takes time

- Don't forget about us
- We will twitter and shout

Then a Serbian drop spoke out loud:
Pristopatsjnost ! Accessibility !
Jedenakost ! Quality !

And finally a quiet drop that needed some more time to find its words said slowly but surely:

"we need to meet
to understand who we are
we need to make that shift
from seperating streams
and excluding drops
from the way things have always been done
to including us all
to becoming one..."

It was silent for a while.
Then the little stream added quietly but firmly:

"The day we fully flow together
I should not have to ask for your support
I should not have to ask for anything anymore
I am water, just like you
We are water, through and through..."

The Main Stream had become quiet.
"He looks tired", the little stream thought. "He needs me.
But he does not understand why or how yet.
I will have to knock on his door again tomorrow.
And I will.
I won't stop now.
This is the time."

Together they sat and watched the sun go down.
And they dreamt of a sea
where many different streams
from all over the world
played with the waves
and many different boats
unafraid of winds and storms
sailed safely into the night.







Stien Michiels

PANEL FIVE – WOMEN WITH DISABILITIES

The members of this panel were: *Helga Stevens: Member of the European Parliament, Co-chair of the Disability Intergroup, Vice-chair of the European Conservatives and Reformists Group and moderator of the panel; Joanne McDonald: Disability Equality Officer, Mencap, Northern Ireland with personal testimony; Ana Peláez Narvaez: CRPD Committee, the Rights of Women with Disabilities and the EU; Katarzyna Ptak: Policy Officer, Gender Equality, Directorate General for Justice and consumers, European Commission.*

Changing the Landscape – Making women and children with disabilities a priority

When Joanne McDonald took the stage to make her contribution to the conference she did so full of smiles and laughter. As a woman with Down Syndrome who has been a champion for the rights of persons with disabilities for many years, and who has worked for the charity, Mencap in Northern Ireland for over a decade she gave a warm and insightful presentation that received a huge round of applause when finished. “Having a disability has its challenges. But it does not mean that I don’t have a full life,” **Ms McDonald** opened by saying.

Ms McDonald told the conference: “A lot of people, a lot of women with learning disabilities, often don’t get the same opportunities in life to learn new things, but my life has been different.”

Drawing on her own experiences of having been supported by her family and community, **Ms McDonald** explained how important it was for her to work changing attitudes to disability and to have the opportunity to keep learning. She talked also of the value of female role models for women and girls with a disability, of why being able to have fun is vital for quality of life, and of how in her lifetime she has felt more included in wider society.

Ms McDonald also took time to highlight some of the barriers that many women with a disability face every day.

Some of the valuable points **Ms McDonald** made to delegates were:

- How culture and TV can help shift attitudes towards disability by promoting positive images of women with disabilities that can help increase confidence.
- Numerous barriers remain, including lack of support and low self-esteem but also overprotective families and support workers who may be concerned for women with learning disabilities who want to pursue relationships.
- For women with intellectual disabilities there can be low expectations and this can lead to not engaging in relationships at all. In addition, if transport isn’t accessible this can mean that forming friendships and relationships is more difficult.
- Another barrier is the laws in many places that make it illegal for people with a learning disability to marry or to have sexual relationships.

Ms McDonald concluded: “We need to promote positive views of women with disabilities. From the beginning of their life.”

After this impactful speech came another very powerful presentation, this time by **Ana Peláez Narvaez** in her role on the CRPD Committee, Rights of Women with Disabilities and the EU. In the first instance, **Ms Peláez Narvaez** mentioned the significance of having a conference session dedicated to celebrating women with disabilities. She reminded delegates of the proportion of persons with disabilities who are female or a child – 48 million in the EU alone.

Ms Peláez Narvaez reflected: “Historically, legislation policies, both national and international, have excluded the issue of women and children when it comes to disability policy.”

The issues affecting women and children with disabilities have been on the margins of society for far too long, she said. **Ms Peláez Narvaez** put questions to the room about advocacy for women. These were: “So, where are we? Why are we being forgotten? Where are our rights? What rights do we have? And who is going to defend them?”

Ms Peláez Narvaez’s key points included:

- Women with disabilities are beginning to fight for recognition of the barriers and discrimination they face, including at a local and national level, but more help is needed from institutions, including within the EU.
- The Committee has identified “multiple, cross-cutting discrimination” due to gender and disability and has decided there is “a huge need for action”.
- There are very serious examples of ‘cross-cutting’ discrimination, including sterilization, with links between its use and legal capacity. Women are victims of abuse yet in many cases have sterilization forced upon them. Female genital mutilation also “has a huge impact” on women with disabilities.
- Institutionalization can have dire consequences for women with disabilities.
- These women need a bigger public role, greater visibility, policies that promote their fundamental rights including to work, and robust protection from violation and abuse.

Ms Peláez Narvaez said: “The issues relating to women and children with disabilities must be mainstreamed in all policy areas.”

Finally, the conference heard a presentation by **Katarzyna Ptak**: policy officer on gender equality, Directorate General for Justice and Consumers. In a detailed presentation **Ms Ptak** gave an overview of the prevalence of disability for women as well as key challenges such as low rates of employment, high rates of poverty, and increased likelihood of being victims of abuse or violence.

Ms Ptak focused her talk on the EU’s Strategic Engagement for Gender Equality 2016-2019, which was adopted in December 2015. The main elements addressed included:

- Five priority areas have been established including labour market participation, reducing pay gaps and poverty, gender equality in decision making, protection against violence, and promoting women’s rights globally. Clear progress indicators and monitoring how Member States perform on these is an important part of the process.
- There are 33 key actions to implement the framework across the five priority areas.

- As part of the implementation process particular attention will be paid to women with specific needs as a result of multiple disadvantages such as living with a disability.
- Violence against women is an important focus and the Commission is acting in a number of ways to address this. Data on the levels of violence “is shocking” but measures to tackle this will include strong data collection, legislation and awareness raising.
- Work is scheduled to take place by the Commission with the Gender Equality Institute to collect better information and data regarding women with disabilities.

Regarding the Commission’s work under the framework Ms Ptak said: “We invite all the stakeholders at local, national and European level to join us in these actions.”

OPEN DEBATE 5

Comments from the floor and panel responses

The closing floor discussion of the conference was short but dynamic and to the point. Panel members responded to 1 overarching theme, namely the unequal status of women and how to ensure that women with disabilities are at the centre of strategy and policy-making.

Responses to ensuring women with disabilities are at the centre of strategy and policy-making included: The first contribution to the discussion was from Luisa Bosisio Fazzi of the Italian Disability Forum. Ms Bosisio Fazzi stressed how often gender is marginal to policy decisions suggesting that politicians need to have it made clear to them that it is important in general, but also for women with disabilities. She said discrimination was often “invisible” and that governments must act to mainstream issues affecting women across policy areas.

Luc Zelderloo, Secretary General of EASPD remarked on how important this final panel was. He then made a point about lack of legal capacity being a “real problem” for women and girls. “That leads to institutionalization, sterilization, forced abortion, and so on,” he told delegates.

Louise Lolo Danielsson, a board member of the European Union of the Deaf drew attention to the issue of women with different disabilities and how something should be done to take this into account. She said there have been no specific policies historically for deaf women yet there were issues to be addressed. “We know very little if anything about the real life stories of deaf women,” Ms Danielsson said and wanted to know if anything was planned in this area.

A point not brought up at any other time was raised by Timothy Rowies representing the European Union of the Deaf Youth. Mr Rowies addressed his point to Ms Ptak in relation to the equality strategy saying that discussions tend to centre around “the two classical genders” when there are “many other gender identities”. He asked: “What are you going to do to address this multiple discrimination?”

Responses to putting women with disabilities at the centre of policy-making included: There wasn’t much time left but Ms Ptak responded to a number of the points brought up. She thanked people for their practical suggestions regarding improving inclusion for women with disabilities. Ms Ptak informed delegates that a session on exchanging of views and ideas on how to strengthen gender mainstreaming

was scheduled for December 15th 2016 during the High Level Group on Disability. “I hope we will discuss many of the issues in more detail.”

On the issue of the “intersection” of inequalities Ms Ptak explained there was a team at the Commission looking at these and there is an action plan to be implemented. She welcomed the opportunity to explore ways to work in the future on the links between inequalities related to gender and disability.

Ms Ptak said: “I need to understand better how we could work together; to look at some possibilities to involve women with particular disabilities in the discussions.”

CLOSING REMARKS

By Pat Clarke, executive officer, Down Syndrome Ireland; Georg Fischer, Director for Social Affairs, Directorate-General for Employment, Social Affairs and Inclusion, European Commission; Olga Sehnalová, Member of the European Parliament and Group of the Progressive Alliance of Socialists and Democrats.

Following this landmark event marking 10 years of the UN CRPD the closing statements reflected the enthusiasm and depth of discussion that took place. **Pat Clarke** began by saying he hoped the conference would “revitalize the process towards full implementation of the convention” and build on the shared conclusion of the positive impact the Convention has had, and can continue to have. **Mr Clarke** praised the Convention for putting “the person at the center” and for aiming at “inclusive societies based on equality for all.”

Mr Clarke highlighted also the steps taken by the EU on implementation and underscored the role of grassroots organisations and disability rights activists “at the forefront” of pushing for inclusive societies. He added that at a time of rising populism in the world, engagement by persons with disabilities is extremely important. He called for fresh actions at a European level to move on to the next stage of implementing the UN CRPD. Among his suggestions on behalf of EDF was the “adoption of a comprehensive agenda for the 2020 to 2030 period to mainstream the rights of persons with disabilities in all policy areas.”

Mr Clarke said: “We look forward to a society that respects the rights of persons with disabilities; a society that leaves no one behind.”

Ms Sehnalová used her time to reflect on the potential as well as the complexity of the European Accessibility Act. The goal was to ensure an ambitious proposal “with the full involvement of persons with disabilities throughout the legislative cycle,” she told delegates. **Ms Sehnalová** spoke of the need for the Act to incorporate the “full range of policy areas” to foster full inclusion and independent living and she also stressed the importance of a mechanism for “ongoing effective and independent monitoring and enforcement.” The task of developing the Act was not an easy one, Ms Sehnalova said. A number of complex issues with ongoing dialogue and exchange of views have been part of the process with more anticipated, she said. Some were necessary because of differences between Member States “as regards to legislation, standards and guidelines on accessibility in place.” Harmonizing the laws of Member States to promote accessibility is central to progress she concluded.

MS Sehnalová said: “The views of people with disabilities who are meant to be the major beneficiaries of the proposals have to be heard.”

Final remarks were delivered by **Mr Fischer**. He told delegates that as his first time at the annual event, he considered it to be “fascinating” and a “landmark”. It was also innovative and “one of the most lively and interesting events I have

attended in this room.” **Mr Fischer** said. It was important for the Commission to receive both the praise and criticism that were represented throughout the conference, he added. **Mr Fischer** summarized a number of points that had resonated with him. The first of these were the wider rights agenda addressed by delegates, the shift from the medical model of disability to a rights-based model, and that “mainstreaming” was highlighted.

Mr Fischer also referred to the “strong emphasis” on gender and the importance of persons with disabilities as role models that were raised during panels and discussions. In addition, he drew attention to the fallout from the financial crisis and recession that followed and how the responses in many countries, including budget cuts “had failed people with disabilities.” Other reflections included on the “interconnection of poverty, social exclusion and employment” and the effect of this on persons with disabilities. He highlighted too the enduring challenges around independent living and deinstitutionalization and why addressing these was vital.

In conclusion, **Mr Fischer** stressed the role EU instruments including the Social Fund can play in relieving some of the negative impacts experienced by people living with a disability. He said also that the message of persons with disabilities being involved across policy areas was both important and had been heard.

Mr Fischer said: “It is important that we mainstream the human rights approach across the EU policies. It is something that needs to be done in each Member State, throughout society, and throughout all the policy areas Member States pursue.”

Before the conference was formally brought to an end a video message was played from Malta, the Member State that would be taking over the European Union Presidency in January 2017. In the short address Justyne Caruana, Parliamentary Secretary for Rights of Persons with Disability and Active Ageing said Malta was fully committed to ensuring that the rights and issues of people across the EU with a disability would be a top priority. She outlined some of the initiatives that Malta had championed recently, including on employment and a number aimed specifically at persons with sensory or intellectual disabilities. **Ms Caruana** added that commitment to an agenda that promoted full inclusion and participation in society through a human rights approach would be a focal point for the new presidency.

Ms Caruana said: “Amongst us and around us there are millions of persons with disabilities who are keenly observing and awaiting our action.”

