



INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

40th anniversary • 1979 - 2019

EUROPEAN DAY OF PERSONS WITH DISABILITIES Brussels, 2019

On **28 and 29 November 2019**, the International Federation for Spina Bifida and Hydrocephalus took part in the European Day of Persons with Disabilities 2019 (EDPD) conference. This event hosted by the European Commission and in partnership with the European Disability Forum was the opportunity to raise awareness on the everyday-life challenges faced by persons with disabilities.

This year the main topics were the preliminary findings of the European Disability Strategy 2010-2020 (EDS), what is expected in the upcoming years and how to achieve sports for all.

Ioannis Vardakastanis, President of the European Disability Forum opened the conference by saying that “the motto leaving no one behind should not be just a motto. It should be part and parcel of real policy and lawmaking” and he highlighted that we need to be ambitious about disability policies by committing to a new Disability Rights Agenda.

On the first day, the preliminary findings of the public consultation on the EDS were presented. The public consultation had three aims: to assess the implementation of the EDS at European and Member States level; to evaluate the strategy according to some criteria (efficiency, relevance, coherence, etc); provide some recommendations for the future.

The public consultation showed that in 7 out of the 8 areas¹ identified, more than half of the actions were achieved. **Education & training and external actions were the two areas identified with the fewer actions implemented**, while 56% of the respondents declared that the situation of persons with disabilities has been improved in the last decade. The public consultation showed that the **key factors** contributing positively to the progress of the EDS are: **political and legal impact of the UNCRPD², advocacy by the NGOs, EU legislation and raising awareness on the activities**, while the hindering factors are limited political will, limited understanding on disability issues by policy-makers and when persons with disabilities are not involved in the policy-making.

The first results of the consultation showed that the current EDS could be improved: with more data on persons with disabilities; monitor more closely the implementation of the actions at the national level; dedicate a specific budget to the EDS; mainstream equality and

¹ Areas identified in the EDS: Accessibility, Participation, Equality, Employment, Education and Training, Social Protection, Health, and External Action.

² United Nations Convention on the Rights of Persons with Disabilities

non-discriminations in all EU policies; involve more persons with disabilities in the policy-making.

Catalina Devandas-Aguilar, United Nations Special Rapporteur on the Rights of Persons with Disabilities mentioned that three gaps were identified when looking at the UN systems: lack of mainstreaming, lack of high-level leadership, lack of capacity of the UN in understanding & addressing the rights of persons with disabilities. She also highlighted that the UN has a framework to support and to set progress for disability rights but that she is concerned by the fact that the international community and intergovernmental institutions are still not committing as they should on the rights of persons with disabilities.

In the afternoon a debate with NGOs took place on what to expect from the EU on disabilities in the next decade. IF was represented by its Board Member **Rasmus Isaksson**. He raised the importance of the Rail Passenger Rights Regulation and the need to remove the 48 hours notice to get assistance. Persons with disabilities should be able to travel equally to all other EU citizens. Two days of pre-notification is not equal access for persons with disabilities.

Our youth representatives had the opportunity to take the floor during the EDPD conference and raise some questions. **Helena Corens**, youth representative of the Flemish Spina Bifida & Hydrocephalus association, emphasised the important link between education & employment and the need to train teachers, carers, students & society that they are all one community.

Navkiran Sirha, our youth representative from the United Kingdom pointed out that we also need to talk about responsibilities, which go three ways: persons with disabilities to each other, the responsibilities that persons with disabilities have towards the EU stakeholders and lastly the EU stakeholders to them.

On the second day of the EDPD, the participants had the chance to discuss how to achieve accessible sport to all. Sports for all is a way of developing inclusion and community and creating friendships, relationships. **MEP David Lega** and Paralympic Champion, shared his own testimony saying that "It is not about winning medals, it's about gaining life".

IF youth representative, **Valmar Ammar** from Estonia raised the question of what can be done to break barriers, so young people with disabilities do not feel self pity and will take responsibility for their lives and bodies. MEP David Lega answered that people with disabilities need to focus on what each individual can do, not on what can go wrong.

Ana Pelaez, Vice-President of the European Disability Forum, called the European Union to be much more ambitious on Disability policy and to no longer ignore women with disabilities. "We are absent from the current EU Disability Strategy, and also from the Gender Equality Strategy. Enough is enough.

In the afternoon, the EDPD closed with the annual Access City Award 2020 Ceremony. The city of Warsaw is the winner of the 10th edition of the Access City Award. **Marianne Thyssen**, Former European Commissioner for Employment, Social Affairs, Skills and Labour Mobility said that "the city is a model for other cities, showing that a lot can be done in a very

short amount of time to make it more accessible for people with disabilities and that commitment can be key to success!".

Ioannis Vardakastanis, suggested for next year to have an award "for cities that have a holistic plan to implement the UN Convention on the Rights of Persons with Disabilities".

It was a pleasure for IF staff and youth members to take part in this year's European Day of Persons with Disabilities conference. We really thank the European Commission and European Disability Forum for hosting and organising this initiative.

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International Federation for Spina Bifida and Hydrocephalus

Consultative status special category Economic and Social Council at the United Nations

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