

REPORT

“MY RIGHTS: Independent living, activism and participation for young people with SBH”

Human rights literacy should be commonplace not only at a high political level but in classrooms and kitchens, parks and cafes. It is only when the citizens know their human rights, that they can actively claim them for themselves.

It is particularly crucial that the young people of today - future leaders of tomorrow - know, use and promote human rights at the local, regional, national and international levels. For young people with disabilities, there isn't a more important tool to promote their rights than the UN Convention on the Rights of Persons with Disabilities (CRPD).

Supporting youth with disabilities is a key priority for the International Federation for Spina Bifida and Hydrocephalus. To increase our efforts, we started offering a training course on human rights and activism to young people with spina bifida and hydrocephalus (SBH) from European countries in 2016.

This year, the training ‘MY RIGHTS: Independent living, activism and participation for young people with SBH’ took place in sunny Lisbon, generously hosted by the Portuguese association for SBH, ASBIHP. From 5 to 7 October, 11 young people from Belgium, Croatia, Estonia, Ireland, Portugal, Scotland, Sweden, and Turkey learned, interacted, practiced, improvised and laughed together under attentive guidance of the international team of trainers that included other young persons with disabilities.

One of them, Anđela Radovanović from the Association of Youth with Disabilities of Montenegro, presented different models of disability and its evolution from a charity concept to a human rights-based one. Anđela also led the session on sexuality and relationships which intended to make clear that your disability doesn't define you and that we are all human beings with the same desires.

Kamil Goungor from the European Network for Independent Living (ENIL) and chair of the European Disability Forum's Youth Committee, further talked about youth emancipation, stressing that having a disability is not an excuse to be inactive and calling on young people to be the vehicle of change they want to see in the society. Kamil presented the history of the Greek independent living movement that was created thanks to the drive and commitment of its founders and despite the dire financial and political situation in Greece today.

The participants were supported by IF to build their advocacy strategies to tackle injustice and discrimination at the local level and present convincing arguments to decision-makers. All the participants developed and presented an advocacy action plan as a final activity of the training, which could be the basis to effectively implement an action in their communities.

Some conclusions and feelings from this training can be summed up as:

- The participants are now more conscious about the potential that the CRPD offers to create a change for young people with SBH
- Lack of experience or funding is not an excuse for inaction. If you want it, you should go and get it! Even if you fail, you will gain experience and meet likely-minded people on the way.
- “Nothing about young people without young people” should be the motto of national associations of SBH all over the world. Youth should be involved and consulted.

Thank you very much to all the participants, speakers and ASBIHP, our member association from Portugal, for their support to organise and develop this training.

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International Federation for Spina Bifida and Hydrocephalus

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