



INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA  
AND HYDROCEPHALUS  
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## REPORT

### **2019 "MY RIGHTS: Independent living, activism and participation for young people with SBH"**

In August 2019, the International Federation for Spina Bifida and Hydrocephalus (IF) has organised its 4th edition of the youth training in which the participants learn about the Convention on the Rights of People with Disabilities (CRPD) and how to make use of it to claim their own human rights.

This training aims to empower young people with spina bifida and/or hydrocephalus (SBH) to become potential advocates at local, regional, national or international level, as they are the future leaders and possibly future managers of Disabled People's Organisations. For young people with disabilities, the CRPD is the most important tool to promote and ensure their rights.

This year, the training 'MY RIGHTS: Independent living, activism and participation for young people with SBH" took place in Tallinn, Estonia, in an accessible and beautiful venue near the seaside and it has been hosted by the Estonian association for SBH, MTÜ Eesti Seljaajusong ja Vesipeahaigete Selts. From 17 to 20 August, 8 young people from Bulgaria, United Kingdom, Turkey, Estonia and Sweden learnt, exchanged ideas and opinions, laughed and worked together during four intensive days. There was an excellent team of trainers that included other young people with disabilities and two of them already collaborated with IF in last year's edition of the training.

One of them, Andela Radovanović from the Association of Youth with Disabilities of Montenegro, presented different models of disability, focusing on the evolution to the human rights-based one. Kamil Goungor also had his second experience as a trainer with IF. He works at the European Network for Independent Living (ENIL) and he is the Chair of the European Disability Forum's Youth Committee. Kamil motivated the participants by sharing his experience as co-founder of the Greek independent living movement. He also stressed that having a disability is not an excuse to be inactive and that independent living is for all persons with disabilities, regardless of the level of support needed.

The new addition to the trainers' team was Rasmus Isaksson, of the Swedish organisation 'Förbundsordförande DHR', who presented practical examples of actions in order to advocate for change in society. Rasmus also clarified some misconceptions about the CRPD to the participants and highlighted its utility.

Divided into 3 groups, the participants prepared an action plan to tackle a specific issue at local level and present convincing arguments based on the CRPD. All the participants developed and presented an advocacy action plan as a final activity of the training, which could be the basis for implementation in their own communities.

There also was a ‘safe space’ for young people with SBH, sessions where women and men separately had time to share their concerns, ideas and experiences about sexuality and reproductive health.

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

- The participants have now basic and necessary knowledge about the CRPD and its utility and its potential, they are aware that the CRPD is a tool they need to know to fight for their rights.
- The topic of sexuality is a very interesting topic for the whole group. Both the ‘safe space’ session on self-perception and sexuality and the presentation on the IF survey were well received.
- As it was pointed out after last year’s edition of this training, “Nothing about young people without young people” should be the motto of national associations of SBH all over the world.

All young people with disabilities should be knowledgeable about the CRPD in order to be well prepared to defend and advocate for their human rights in any situation throughout their lives. IF and its member organisations are aware of the importance of empowering young people with SBH, as they are the future of our community!

Thank you very much to all the participants, trainers and to our Estonian member for their support to organise this training successfully.

**IF ivzw**

International Federation for Spina Bifida and Hydrocephalus

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Cellebroersstraat 16 - B-1000 Brussels

T: +32 (0) 2 502 04 13 - F: + 32 (0)2 502 11 29

[www.ifglobal.org](http://www.ifglobal.org)