



Tune up Your Organisation: Fight for Your Rights



Report of the 10th study session run by the
International Federation of Hard of Hearing Young People (IFHOHYP)
in co-operation with the
European Youth Centre of the Council of Europe
European Youth Centre Strasbourg, 17 – 22 November 2014

This report gives an account of various aspects of the course. It has been produced by, and is the responsibility of, the educational team of the study session. It does not represent the official point of view of the Council of Europe.

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Who We Are

IFHOHYP is an international non-governmental federation for national and regional youth organisations that are dedicated to hard of hearing young people throughout the world and is independent of sex, race, religion, nationality and politics. First established as a Committee in 1968, it changed its name to a Federation. Our greatest priority is improving the quality of life of hard of hearing youth worldwide and advocating for their rights at all levels of society. The work of IFHOHYP is guided by the UN Convention on the Rights of Persons with Disabilities.

IFHOHYP works on advocacy, awareness-raising, and educational levels providing personal and professional development opportunities for members. We strive for empowerment of hard of hearing young people, for visibility and representation of youth with disabilities in European and international youth & disability rights work. We raise disability awareness on national and international level through activities run by, with and for hard of hearing young people aged from 18 to 35.

IFHOHYP was the first international youth and disability organisation to actively cooperate with the Council of Europe, an intergovernmental organisation that works towards human rights, democracy and the rule of law. Often we have been the only voice of youth with disabilities in political and advocacy discussions on the global level. IFHOHYP works closely with an Advisory Council on Youth within the Council of Europe which is a statutory body comprised of 30 youth NGO representatives that can assist in developing the agenda of the youth sector and other sectors of the Council of Europe.

IFHOHYP is an associate member of the European Disability Forum and an observer member of the European Youth Forum where it was the first disability youth organisation. Since 1990's IFHOHYP is actively involved in the UN World Youth Forums, UN World Youth Conferences. It was represented at the UN High Level Meeting on Youth (2011) and received the UN Special ECOSOC Consultative status in 2013. We cooperate with Global Partnership on Disability and Development, IFHOH, EFHOH, and International Disability Alliance.

IFHOHYP started as a small international federation of a few member organisations, most of them in Europe. Today IFHOHYP constitutes more than 20 organisations from Europe, Canada, Asia and Africa; its focus shifted from social and peer support activities to international advocacy, non-formal education training and human rights work. Since 2000s, thanks to its quality educational projects IFHOHYP started expanding its membership in Africa and Asia, and the amount of members is increasing.

Our Mission

- To promote equal rights for hard of hearing young people. Hard of hearing young people have the right to a good education, freedom of choice, the right to equal treatment at labour market, necessary technical aids and support.
- To defend the interests of hard of hearing young people and express them towards international bodies.
- To serve as a platform for cooperation and exchange of information between organisations of hard of hearing youth.
- To encourage a better understanding of hard of hearing young people and their problems among the general public.

The study session

As part of the IFHOHYP annual work programme, a youth conference should take place to empower hard of hearing youth workers and their organisations from different European countries with skills and methods to raise awareness and access to social rights in their respective countries. The organisers of the study session, both the IFHOHYP board and the planning team, also wanted to provide an opportunity for hard of hearing youth organisations within and outside of Europe to connect, to strengthen their organisations and the voice of hard of hearing in Europe. As a result, the 10th study session: *Tune up Your Organisation, Fight for Your Rights* was held.

Accordingly with the IFHOHYP Strategy 2009-2014, IFHOHYP's organisational development goals are:

- to make communication and exchange of information within as well as outside of IFHOHYP, more effective and efficient;
- to provide continuous training to hard of hearing youth in order to empower them to work towards their full participation in society.

In terms of advocacy, our aim is to train multipliers and active citizens who are able to develop strategies on access to decision-making and implement them, allowing themselves and others to fully participate in the decision-making processes through contribution to the European Disability Forum, the European Youth Forum, the International Disability Alliance, the UN CRPD Committee policy work. All the external advocacy goals can be achieved only by capacity-building and improving sustainability of IFHOHYP member organisations internally, as well as by close cooperation/co-working with the majority of hearing people and mainstream non-disabled youth organisations, thereby striving for the ultimate goal of IFHOHYP – full inclusion in the society. For hard of hearing youth who face challenges in managing their regional/local organisations, it is difficult to find the energy and motivation to continue voluntary work on a long-term basis, not to speak of managing sustainable participation by hard of hearing youth, or finding educational opportunities to improve their management skills, advocacy skills or disability rights work on an international level.

The increasing size of IFHOHYP (from 9 countries in 2004 to 26 in 2012), changing needs and situation of its member organisations (in part due to crisis and less financial support) as well as the growing amount of emerging organisations of hard of hearing youth, call for improved management of processes both on the international and membership levels, as well as passing on the tools to member organisations. Furthermore, some youth organisations are on a verge of closure because of lack of funds or pressure from the adult chapters (Germany).

In order to achieve our strategic goals, we found it crucial to organise the study session with a focus on organisational development. This activity was built upon previous study sessions, in particular on: “*Putting hard of hearing youth on the Map of Europe*”; “*Building communication for hard of hearing youth: breaking down barriers and stereotypes*”, and the preceding study session: *Striving towards*

policy impact, awareness raising and access to social rights. This study session had a great impact on needs assessment within IFHOHYP and its planning of policy work.

Aim and objectives

The aim of the study session was to empower young hard of hearing leaders with competences needed for organisational development in order to enable their sustainable participation and disability rights work on local, national and international levels.

The study session objectives were:

- ✓ To explore and analyse what it means to run, develop and manage the organisation by, with and for hard of hearing youth: what challenges and risks are specific for youth disability organisations?
- ✓ To identify the most urgent needs of hard of hearing young leaders in organisational development and disability rights advocacy;
- ✓ To share experiences and exchange examples of practices in organisational development, capacity-building and policy/human rights work;
- ✓ To identify tools needed by participants for consolidating organisations and sustainability of participation by hard of hearing youth;
- ✓ To facilitate partnerships between young people with disabilities and other minority or marginalised groups;
- ✓ To equip participants with skills and competencies in organisational management, such as: self-management, decision-making and problem-solving, teamwork, leadership, strategic planning, conflict management, coaching, and mentor systems;
- ✓ To provide participants with an opportunity to explore human rights education and the No Hate Speech Movement Campaign methods as effective disability rights advocacy and anti-discrimination tools that can be applied within and outside participants' organisations.

Outcomes

The outcomes of this study session were primarily made visible by the creation of four videos promoting the issues faced by deaf and hard of hearing youth, as part of the No Hate Speech Movement Campaign. These videos were uploaded on the IFHOHYP website: <http://www.ifhohyp.org/?p=705>.

Moreover, by the end of the session, eleven project ideas were developed in cooperation by thirty-five participants; most of them are related to the empowerment of hard of hearing youth with skills necessary to be active citizens. Examples include English language courses, recruitment of volunteers through motivational communication techniques via coaching and/or mentoring, personal and social development of hard of hearing youth from building teamwork and group

dynamics. There are also projects related to accessible communications, networking opportunities between hard of hearing youth and other disabled youth in Europe, promoting the visibility of hearing loss. The immediate impact of this study session is the ability to provide a non-formal educational setting in which participants can share experiences and exchange ideas about their projects.

The participants learned about the concepts of human rights, social inclusion, coaching and mentoring, online movement against hate speech, and other skills to help them build a strong foundation where they can start a campaign to influence policy makers in order to defend their rights and interest as deaf and hard of hearing people.

There were many opportunities for networking so participants could engage in discussions, sharing their experience work from their own hard of hearing organisations in their countries. Participants formed strong relationships and bonds to the extent that they came together to develop common project ideas and practices to be applied to their countries. Eventually, committees were formed to continue this work to take the next step forward in ensuring voices of deaf and hard of hearing youth are heard worldwide. It is with great sense of pride that we were able to achieve the intended outcome: whereas participants could plan and develop concrete strategies to tune up their organisations and raise awareness about hearing loss on local, national and international levels.

Problems and Issues Faced by Deaf and Hard of Hearing Youth

Despite the huge progress achieved in the recent years in the quality services and technology, deaf and hard of hearing youth still face many barriers in promoting their social inclusion which became a growing issue affecting their daily lives. This study session covered a wide range of life aspects where social inclusion lies within and aimed to create forum for discussion and exchanging on how hard of hearing youth are working to improve the quality of life in their countries. Representations from different countries with a variety of inputs helped to stimulate discussions and exchange of practices and ideas amongst participants.

Identifying barriers

Discussions with participants illustrated both the similarities and differences in definition of social inclusion. Participants exchanged stories and experiences with good practices and tools to promote services and enhance social inclusion. There was a consensus among participants that social inclusion is when deaf or hard of hearing youth feel respected on the social level, which means providing services for deaf and hard of hearing in order to have good access to education, health, leisure facilities. These sectors were explored in terms of their limited support of services available.

A. Education

Participants highlighted the issues of communication barriers where technical equipment, like induction loops or speech-to-text translation are not available in many counties like Turkey, or small cities and regions where these services are almost unheard of. The participants also pointed out the issue of the interpretation provision. For example in Russia, they offer only 40 hours of free interpretation in the whole year. This is insufficient to assure adequate access to the information and it also limits free choice to choose your own education. Some colleges or universities may not have communication access available and thus deaf and hard of hearing youth are forced to choose options where there are services available. For those who do attempt to go through the programme, the journey is most difficult and they are placed at a disadvantaged compared to their peers.

B. Health

In the medical sector, there is agreement that there is a certain amount of accessibility at hospitals and clinics but this accessibility varies in different levels. For example in Canada, there is always a possibility to miss your name when you are called up through the announcement. Another issue that affects the quality of services is the lack of priority. For instance, in Germany, your bank account must not be more than 2600 Euros if you apply for insurance reimbursement from purchasing hearing aids, FM systems or hiring sign language interpreters. In Turkey, patients have to pay their own costs for interpreters and many cannot afford this service. As a result, they attempt to communicate with doctors, leading to many misdiagnosis or incorrect prescriptions, further complicating their health issues. In Sweden, on the other hand, sign language interpreters are provided at any time. In Russia, even though the law recognizes the right of hard of hearing people

to get hearing aids, it remains theoretical more than practical and it is believed that there is an issue of budgetary measure to put a limit on the provision of services.

C. Cultural and Leisure Life

Subtitles are not available in the local language, including foreign films which are most often in English. There is no accessibility in understanding the instructions for a variety of sports (i.e. horse-riding, swimming). Inadequate communication access at public facilities, such as airports, where it is difficult to hear the announcement, adds to the anxiety of deaf and hard of hearing youth in knowing where they should be going.

Transition to Development of Solutions

After sharing of experiences and exchange of information, participants discussed human rights and what they can do address social inequality. Both deaf and hard of hearing youth face the same issue, which is accessibility to communication and information. However, they each require different support. For hard of hearing, there are additional standards to consider like the acoustics of the room or speech-to-text translation. For deaf people, they need sign language interpreters and access to adequate lighting to be able to see the person. Solutions were then brainstormed to address these issues faced in each sector.

General Communication Solutions

Hard of hearing and deaf people should educate the people around them about communicating with them.

One solution is to improve awareness in the family, and among friends, and for example to learn to teach sign language.

Another problem is the background noise (for example from the TV or the radio). One of the solutions is for example to think of an architectural structure against the background noise, for example a small room without echo.

Another problem is the impossibility to use new technologies, for example Skype. One of the solutions is to improve the development of technology, for example giving more economic bonus for researching solutions these problems at university.

It is also important to have well-lighted places, because both deaf and hard of hearing people need to see the face and the body of the speakers.

Internet connections must be more stable and all countries should increase their Internet bandwidth, because some of the useful services need a stable and fast Internet connection.

A. Education

Education is the most important thing, of course, to change attitudes. It has to start from the very small ages in kindergarten to teach the representation of the disabled people and to consider them as a full person. The non-formal education field is very important in this process.

The major communication issue in education is that the access to technical equipment such as to have hearing aids, induction loops or FM systems.

The second major problem is that teachers and our colleagues in the class do not have information how to communicate with us. Hard of hearing and deaf people, and their organisations should work on this problem, and they should visit schools and universities to provide information about communicating with hard of hearing and deaf people.

- ❖ In the Czech Republic, a university uses speech-to-text software to save lectures.
- ❖ Most countries try to avoid to have special schools for hard of hearing and deaf people. Generally, they prefer to support hard of hearing and deaf students via interpreters and

speech-to-text services in mainstream schools. It is a good thing because it provides equal education to all the people. If hard of hearing and deaf persons want to learn sign language or want to improve their speech or written language, the governments can provide additional courses, or classes, but not separate schools. It will be easier and cost effective, and it will be more inclusive.

B. Health

One of the most important problems of hard of hearing and deaf people facing is when they need to go to the hospital for medical examination. Most of the countries do not have interpreters, note takers or any supportive communication devices in the hospitals. Hard of hearing and deaf people want that their medical problems to be identified or solved, they would like to explain this to the doctor, but they have communication problems with them.

- ❖ Canada provides a medical kit to all hard of hearing and deaf people. If hard of hearing or deaf people cannot for any reason communicate, they will bring this medical kit with them, and in the medical kit they have a sign "I am deaf" and with a symbol. The most important thing is that this helps the doctor to know how to communicate with the deaf people, it has all the simple instructions on how they should be communicating with deaf people, by looking at the face, not turning round, and also there is a note pad and a pen provided in the medical kit so there will always be something available to write on.
- ❖ In Sweden, the situation is quite acceptable compared to other countries. The interpreter service has a kind of priority list, where visits to the doctor are very highly prioritised. So one can almost always get an interpreter to go to the doctor. The second place on this priority list is to get an interpreter in work situations, for meetings for example, to be able to participate in meeting during your workdays. On the third place on this priority list is everything you do in your spare time after office hours if you want to go to a party or celebration of some sort, if you want to take riding lessons or go to the theatre.
- ❖ It is also noted that if a country ratified the Convention of the Rights of People with Disabilities of the United Nations, hard of hearing and deaf people can go to court, and they can file a case on the basis of human rights. A deaf person in Germany went to court to ask for a free fire alarm in the buildings, and he was successful. After this example, Germany changed its insurance rules to include fire alarms for hard of hearing and deaf people recently.
- ❖ Spain has just started to provide an online remote interpreting service for the hospitals.

C. Leisure

The most important problem about theatres, cinemas and TV is subtitling. Some countries could solve this problem by providing online subtitling. This can also apply for sign language interpreting. It is a cost effective solution, and it does not require a lot of technical equipment at cinemas or theatres.

One of the common problems in some countries is that although these countries provide free or very cheap speech-to-text service, it seems there are not enough speech-to-text service providers in these countries.

- ❖ These countries should try to have more speech-to-text service providers. Government and NGOs should work on this problem.
- ❖ Palantyping is the most effective way to provide speech-to-text service, but it is only available for English. For other languages, alternative speech-to-text systems can be used, such as velotyping and stenotyping.
- ❖ Automatic speech-to-text computer programmes should be improved. They are not working well on group works, or in noisy environments. But they hold the promise to improve, so they should be supported by governments and NGOs.

Politics

It is suggested that young hard of hearing and deaf people should be more active in political life. Russian participants explained that the culture and the problems of hard of hearing and deaf people should be presented by themselves. In governments and governmental organisations, we need to have more hard of hearing and deaf people who know our culture and problems. About hard of hearing and deaf people's problems, they should be prioritised. Hard of hearing and deaf people should avoid trying to solve too many things at the same time. They should find the most important problem for them, and they should do lobbying about these problem to politicians and policy makers.

Developed Projects Ideas

1. Special Fashion in Russia

The idea is to make a fashion exhibition with disabled people as models. This would raise the self-confidence of disabled people such as people who wear glasses or hearing aids or use wheelchairs. These people sometimes try to hide these devices. This project will help to show them that it is possible to be beautiful with these devices, and they should not be ashamed to use them. The project will raise awareness of different images of people with disabilities and change the attitude of society.

2. Centre for Experiencing Disability in Russia

This is a centre for people who have no disabilities. They could come to the centre and experience how it is to have a disability; for example, to be blind, to be deaf or to be in a wheelchair. They will see how to go over different bumps like the people in wheelchair, they will touch materials without seeing them, and they will experience how it is to live without sound. With this project, the society's awareness can be raised through interactivity and education. The visitors who are coming to this centre could be school pupils, students, researchers, people who work in social services, so all different kind of people who would be involved or who would be interested in learning more about this. There are some similar centres in the world, but they focus on one disability only. This project tries to include all disabilities as much as possible.

3. Meeting on an island between Sweden and Finland

This is a joint project between Swedish HoH association and Swedish Speaking Finnish HoH association for young people. This is in order to learn about leadership and empowerment, and of course to meet others who are in the same situation as us. The aim with this seminar would be to improve leading abilities and empowerment among hard of hearing youth. We also have a greater aim to make this into an annual happening for youth hard of hearing people in all Nordic countries. Participants should improve their ability to become active members of the society, wherever they live. This seminar will also give them the tools to spread information in their local regions.

4. English course in Washington DC, USA

This is a two-week English course, which will be arranged by four countries: Armenia, USA, Canada, and Italy. This project will be implemented in cooperation with the Gallaudet University, in Washington DC, USA. The Gallaudet University's buildings will be used for accommodation and courses. Every country can send six people as students to join this course. The students that are interested to be interpreters will learn the international sign language. It is crucial to find teachers who have experience to teach English hard of hearing and deaf people. This project team has already two teachers who are hard of hearing themselves.

5. Deaf Art Exhibition in Istanbul, Turkey

The plan is to arrange a big exhibition of deaf artists' artwork and also the people who would come to view the exhibition would be all types of people, so disabled and non-disabled people and they

would pay a little bit of money to visit the exhibition and also to buy the artwork. That money would then be used to help hard of hearing, deaf and disabled people go to university. The people that visit and see these art works, they would then begin to understand more about deaf and hard of hearing people's culture. We hope to bring this on to an international scale so that we could tour this as part of bigger contemporary art exhibitions.

6. Cultural Centre in Istanbul, Turkey.

The aims of this culture centre are to help hard of hearing and deaf people's in tackling the unemployment problem, to raise awareness about hard of hearing and deaf people in the local society, to provide a small and free library that contains books about hard of hearing and deaf culture. The staff of the Culture centre will be hard of hearing and deaf people mostly. It is also planned to have some seminars in this centre to integrate hard of hearing and deaf people in society. It can also contain some art workshops such as sculptures and paintings by deaf and hard of hearing people.

7. Exchange week between the Netherlands and Germany

The main idea is that the German and Dutch associations are going to start with a programme, and that they would like to do a joint week-long exchange activity where they have many sports and cultural activities, but also workshops and so on. It will help to come together and to work together and learn from each other. A long version of their slogan is that: "We want to do this exchange in order to create a space for the participants to exchange culture and take the needs of hard of hearing people into consideration."

8. Spanish sign language theatre festival in Madrid

The aim is to create a theatre that is accessible for deaf people. This theatre will provide sign language theatre presentations without interpreting. The reason is that there are a lot of deaf and hard of hearing youth that do not have the opportunity to go and see quality theatre. They do not have access to culturally significant literature and historical material of Spain. We would like to encourage them to taste some more of Spain's culture and this is one way to do it.

9. Summer camp for hard of hearing from Finland and Poland

The summer camp would take place either in Poland or in Finland. The background idea is to improve the English skills of the participants. There will be some outdoors activities also, in order to enhance the participants' self-confidence. Part of the programme will be a Living Library event where Polish and Finnish young hard of hearing people can tell their stories. After the camp participants will be divided into pen pals, each participant would have a pen pal and they could keep in touch with each other by e-mails or letters, and they would be staying in contact for the rest of their lives.

Summary

To put it in a nutshell, the study session was also able to raise awareness about communication issues on many different levels. We started on a high level and got positive feedback about that. But as the recommendations which are listed above show, there is still a lot to do and we will be happy to improve our skills in further study sessions.

Two things were made possible to be discussed at the study session which would not have been able to be discussed without proper support:

1) Do hard of hearing and the deaf young people have the same needs?

This could be proved by many projects planned by groups of mixed communication preference.

2) Why do deaf people have so much space in communication?

Hard of hearing participants could see and feel the abilities of the deaf to express their opinions and needs in a stronger way and learned to speak up more for their wishes and dreams. This also can lead to stronger facilitation and development of the respective organisations at home.



Useful materials and links

1. Compass - Manual for human rights education for young people.
<http://eycb.coe.int/compass/>
2. Priorities of the youth sector of the Council of Europe 2014-2015
<http://www.coe.int/en/web/european-youth-foundation/coe-themes-and-youth-sector-priorities>
3. An overview of the differences between coaching and mentoring
<http://www.management-mentors.com/resources/coaching-mentoring-differences>
4. *How to Win Friends & Influence People* – Dale Carnegie
https://en.wikipedia.org/wiki/How_to_Win_Friends_and_Influence_People

List of Participating Organisations

Organisation	Country
The Voice of Silence NGO	Armenia
Canadian Hard of Hearing Association	Canada
Czech Union of Deaf	Czech Republic
Finnish Federation of Hard of Hearing	Finland
Svenska Hörsselförbundet rf	Finland
Bundesjugend	Germany
A. Fa. M. U. T.	Italy
SH-Jong	The Netherlands
Surdus Loquens	Poland
Romania Connect	Romania
FADCY	Russia
All-Russian Society of The Deaf	Russia
Madrid Federation of the deaf (FeSorCam)	Spain
Aransbur	Spain
Unga Hörselskadade	Sweden
Jugehörig	Switzerland
Deaf academy for education and sport	Tunisia
Cochlear Implant Association	Turkey
Hard of Hearing People and Their Families Association (IED)	Turkey



Daily Programme

Sunday, 16 November 2014

20:30 Arrival of participants/Welcome evening

Monday, 17 November 2014

09:15 Opening and introductions
 10:45 Break
 11:15 Group building activities
 13:00 Lunch
 14:30 Presentation by national groups of social inclusion in their countries
 16:00 Break
 16:30 Presentation by national groups of social inclusion in their countries
 18:00 Reflection groups
 19:00 Dinner
 21:00 Organisational share & intercultural party



Tuesday, 18 November 2014

09:15 Non-formal education and its role in HOH community
 10:45 Break
 11:15 Non-formal education and its role in HOH community
 13:00 Lunch break
 14:30 Presentation by national groups of social inclusion in their countries continued
 16:00 Break
 16:30 IFHOHYP Presentation
 18:00 Reflection groups
 19:00 Dinner



Wednesday, 19 November 2014

- 09:15 Human rights education
- 10:45 Break
- 11:15 Strategic planning
- 13:00 Lunch break
- 14:30 Organisational development/motivating people
- 16:00 Reflection groups
- 16:30 Free afternoon in the city
- 19:00 Dinner



Thursday, 20 November 2014

- 09:15 No Hate Speech Movement Campaign
- 10:45 Break
- 11:15 Creation of video against hate speech
- 13:00 Lunch
- 14:30 Creation of video against hate speech
- 16:30 Free afternoon
- 19:00 Dinner in the city



Friday, 21 November 2014

- 09:15 Creation of video against hate speech
- 10:45 Break
- 11:15 Competences market (coaching and mentoring; teamwork)
- 13:00 Lunch
- 14:30 Fundraising
- 15:30 Project management
- 17:00 Break
- 17:30 Development of project ideas
- 18:00 Reflection groups
- 19:00 Dinner

Saturday 22 November 2014

- 09:15 Development/presentation of project ideas
- 10:45 Break
- 11:15 Presentation of project ideas
- 13:00 Lunch
- 14:30 Presentation of the Council of Europe publications and materials
- 15:00 Evaluation
- 19:00 Dinner & farewell party

