

Edited by Marcel Beldijk, president of EFHOH and Niels-Henrik M. Hansen.

Deadline for the next newsletter is September 15th /2015.

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JUNE 2015



## EFHOH PRESIDENT LETTER

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### EFHOH AGM AND CONFERENCE 2015 IN ESSEN, GERMANY

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### ESSEN DECLARATION 2015 ACCESS TO HEARING AIDS IS ACCESS TO OPPORTUNITY

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## EFHOH President letter

### EFHOH Annual General Meeting 2015:

Access to Hearing Aids is Access to Opportunity, on behalf of the 51 million Europeans with hearing loss we, at our Annual General Meeting (AGM) 2015 in Essen, Germany, signed the EFHOH Essen Declaration 2015. We are calling upon the European Union, national governments, and parliaments for affordable, good quality, professionally approved Hearing Aids, ALD, and the training and support standards to use them successfully. It will be fantastic when EFHOH members share their lobbying success stories using our new EFHOH declaration.

At our AGM 2015 in Essen, we also said "thank you and goodbye," to our treasurer, Ritva Liisa and our secretary, Jan. They both did a great job for many years. We are happy that we can say "welcome," to Aïda and Richard. Aïda will be our new EFHOH secretary and Richard will be our new treasurer.

A big thanks to DSB, our member organization in Germany, for organizing the EFHOH AGM Conference Day 2015. It was a great success! More news about the EFHOH AGM 2015 can be read in an article written by Aïda.

Keep a date in your diaries free for the next EFHOH AGM 2016 during the weekend of Friday the 1st and Saturday the 2nd of April in Paris. We the EFHOH board, are looking forward to meeting you in Paris.

### EFHOH Intern:

On the 5th of May, Lidia and Marcel had the opportunity to say "thank you and goodbye," to our first intern, Ed Spragg. Ed did a great job and he had made an updated version of the EFHOH State of Subtitling 2015. As the EFHOH board, we are very happy that we are able to continue our co-operation with Action on Hearing Loss (UK) and that we, for this summer and the next summer, will have an intern that works one day a week for the EFHOH based in London.

### Human Rights Train the Trainers Training:

There has been a popular demand for a place at the IFHOH Human Rights Training and in recognition of the high level of interest shown, we will now be holding two training sessions in Copenhagen during the week of 19-23 October 2015. It is heartening to receive many nominations as it shows that there is a lot of interest in the UN CRPD. Louise Carroll, our IFHOH board member, will be the trainer and Marcel Bobeldijk the co-trainer.

### EDF news:

On 30-31 May 2015, the EDF Annual General Assembly in Warsaw, Poland gathered representatives from the disability movement from all over Europe as well as representatives of European institutions including the European Commission, the European Ombudsman, the Agency for Fundamental Rights, and the Polish authorities. The EDF AGA 2015 hosted an active debate on the implementation



of the rights of persons with disabilities in Europe and its member states. EDF and its members also adopted a resolution calling for the establishment of a Directorate for the implementation of the UN Convention on the Rights of Persons with Disabilities in the European Union, and a resolution calling on the European Union to immediately ratify the Marrakesh Treaty.

We at the EFHOH are very happy that the EDF also represented the 51 million Hard of Hearing People in Europe at the 8th session of the UN Conference of State Parties, which took place at the UN Headquarters in New York. This year's theme was "Mainstreaming the rights of the person with disabilities in the post-2015 development agenda."

#### UN CRPD news:

Lidia and Marcel worked very close together with the EDF staff to finalize the answers to the list of issues and to prepare for the session of the UN Committee at the end of August in Geneva. Lidia and I will represent the EFHOH at the UN Committee session and the different side events. Please do not hesitate to contact Lidia or me if you would like to contribute or if you have any questions. We also need your support in our communication work and our advocacy towards the European Parliament, the European Commission, and to the UN CRPD committee.

#### European Standard of Services Offered by Hearing Aid Professionals (EN 15927) open for revision:

During the summer months of 2015 the French Normative Institute, AFNOR, will send you a request to share your opinion on the need of revisions for the "EUROPEAN STANDARD EN 15927 (ICS 11.180.15 August 2010) Services Offered by Hearing Aid Professionals," since this standard is now five years old.

We kindly request you to advise them to open this standard for revision for the following reasons:

- Since the practice in the field has changed and the standard is only implemented in very few countries, there is an urgent need to adapt the standard to current professional practices.

- The standard does not focus enough on satisfaction evaluation and transparency towards the end user.
- The standard has too much focus on diagnostics while the focus should be far more on professional services for hearing aid fitting.

We the EFHOH board, will also inform you by letter and we are now in the process of making a new survey that we will be sending soon to all our members. Please contact us if you have any questions or comments related to the European Standard of Services Offered by Hearing Aid Professionals.

Twitter, Facebook, and Impact Report 2014:

We invite you to also follow the EFHOH via Twitter and Facebook including some of the EFHOH board members, the addresses are:

EFHOH	@efhoh
Marcel Bobeldijk	@marbob32
Lidia Best	@best_lidia

Of course you can also follow our latest news via our EFHOH Facebook page.

It would be great if you share the EFHOH Impact Report 2014 with all your volunteers and your contacts. Please contact us if you would like to have the paper version of the EFHOH Impact Report 2014.

#### Call for the next EFHOH newsletter:

If you have an article for one of the next EFHOH newsletters that we will publish in 2015, please send it to us! We also make the EFHOH newsletter for all your volunteers at your national and local organizations. You can send your article to our editor Niels-Hendrik. His email address is: [nhmh@learning.aau.dk](mailto:nhmh@learning.aau.dk)

Dear EFHOH friends, we hope that you will have a great summer!

Warm regards,  
Marcel Bobeldijk  
EFHOH president.





## EFHOH **AGM** and **Conference 2015** in Essen, Germany

On April 11th 2015 EFHOH's AGM took place at Hotel Franz in Essen.

EFHOH is still working to help countries in Europe building up national Associations for Hard of Hearing and has got two new members during the last year, those are Iceland and Croatia. A warm welcome!

Sadly one member has also left the EFHOH cooperation, when Italy decided to give up their membership.

The main issues for EFHOH are in particular human rights and accessibility including access to audiological treatment but also access to assistive listening devices (ALD). This is why the delegates approved the Essen Declaration, which state that "Access to hearing aids is access to opportunity" [http://media.wix.com/ugd/c2e099\\_13e3b120ba6b4518a5567ce2287cc593.pdf](http://media.wix.com/ugd/c2e099_13e3b120ba6b4518a5567ce2287cc593.pdf)

The EFHOH Board for 2015 – 2016 is:

President, Marcel Bobeldijk, Netherlands.

Vice president, Lidia Smolarek-Best, England.  
Secretary, Aida Regel Poulsen, Denmark (elected 2015).  
Treasurer, Richard Darbéra, France (elected 2015)  
Board member, Jaana Linna, Finland.

Harald Tamegger, Austria, was elected as a Chairman of the Nomination Committee.

The 2016 AGM and Conference will be held in Paris in France, and it was decided, that 2017 AGM will be held in Dublin, Ireland.

On April 12th 2015 EFHOH Conference took place at Hotel Franz in Essen.

The conference was nicely organized by Deutscher Schwerhörigenbund, DSB.

We were about 160 people in the Conference Room facilitated with neck loops and good interpretation from German into English and vice versa and able to choose the language we preferred to listen to.



We were also provided with Speech To Text – STT – interpreting in both German and English.

All of this made the Conference smooth and easy to participate in.

Many well skilled speakers presented different angles of Human Rights, accessibility and participation and what this means to people with hearing loss.

Speakers were:

Dr. Ulrich Hase talking about Convention on the Rights of Persons with Disabilities and it's meaning to people with hearing impairment.

Dr. Martin Danner talked about Participation of patients in the public health system.

Jakob Stephan Baschab did a presentation on Education of hearing-aid acousticians in Germany.

Dr. Hannes Seidler spoke about Accessibility – Key positions towards inclusion.

Renate Welter presented how Vocational training of Speech to Text Interpreters is carried out in Germany.

Silvester Popescu-Willigmann did a presentation on En route to an inclusive job market.

All speakers described their topics from a German point of view, how things work in Germany on these topics, and the situation in Germany seems easily related to status in many other European countries.

After lunch we heard statements by two political representatives:

Ms. Manuela Grochiowak-Schmieding (Speaker of Bündnis 90/The Greens in social political affairs, Germany) and Ms. Dr. Renate Sommer (Member of the European Parliament, CDU, Germany).

And it does take a lot of political work to implement inclusion in each of the European Countries. This is not just

a matter of paperwork but needs to be implemented in everyday life everywhere.

We then had 3 very interesting workshops about : Health System (with Dr. Harald Seidler, chair of DSB)

Accessibility (with Dr. Hannes Seidler) and Job market (with Silvester Popescu-Willigmann)

Time seemed too short for these three workshops since many questions and remarks came up.

It still proved that the topics are very important to all of us to work on.

The Conference ended with a presentation of the Essen Declaration, discussion about the declaration which was then signed immediately after the Conference closing remarks by Marcel Bobeldijk, President of EFHOH.

During breaks there was a nice exhibition "Market of Opportunities" showing new technical solutions to hear better, new ideas about apps for STT, what is possible within the area of ALDs.. and there were also stands showing pedagogical work from institutions working with children with hearing loss (Leben und Lernen) as well as where to get help if your hearing difficulty causes you mentally distress e.g.

Very nicely balanced between the need of technology as well as pedagogical/psychological methods.

The over all impression of the Essen conference is, that being at a conference with many other people with hearing difficulties and learning how communication can be organized in a way that everybody is being heard, listened to and understood makes the different discussions equal.

On Sunday 12th of April there was a guided bus tour around Essen before a farewell lunch at the Hotel Franz.

Thank you, DSB, for a very nice AGM and Conference in Essen. We are looking forward to AGM and Conference next April in Paris.

Aïda Regel Poulsen  
EFHOH secretary



## ESSEN **DECLARATION** 2015: ACCESS TO HEARING AIDS IS ACCESS TO OPPORTUNITY

11 April 2015, Essen, Germany.

The delegates attending EFHOH AGM have signed the ESSEN DECLARATION, a joint statement of hard of hearing community in European Union.

The Declaration calls for European governments to guarantee access to affordable, good quality, professional approved hearing aids, ALDs, as well as the training and support standards to use them successfully. It builds on UN Convention on Rights of People with Disabilities and specifically Article 5 remembering that hearing aids enable people with hearing loss live fulfilling lives.

Another important aspect of this communication is access to rehabilitation and quality of hearing aids fitting. This is integral part of the process and must not be forgotten, this is why EFHOH supports EU Standard (EN 15927) 'Services Offered by Hearing Aid Professionals' which sets out the minimum standards on fitting process we should expect from hearing aids professionals.

For a few years, EFHOH Board, in communication with members, has been aware of differences between different European countries in terms of accessibility, affordability and funding rules in relation to hearing aids.

We believe that everyone should have access to hearing aids when they need them in order to live independently and to sustain employment, education prospects.

We have also become aware of reversal policies in some countries, making it more difficult to obtain a good quality of hearing aids as well as complete removal of the access in the health services as the case with UK health board in North Staffordshire. We also received a complaint from Netherlands where parents of hard of hearing children are

asked to contribute to cost of hearing aids, they were not required to do so previously. Those are reversal policies which provide a negative impact on the wellbeing of the hard of hearing people.

Another example came from Poland, where quite often hard of hearing people need to cover full cost of hearing aids at the point of purchase and then claim some money back, which we feel is pricing many people out of the opportunity that comes with access to hearing aids.

The Declaration states: . For 51 million hard of hearing people in the European Union this right can be best fulfilled through state-funded provision of hearing aids and the proliferation of assistive listening devices (ALD).

What does state-funded provision mean in practice? In EU, we have state-funded, universal insurance or other means of reimbursement for hearing aids. While they are different ways of receiving reimbursement, they all have something in common; they are often part of health policies endorsed by the State. In practical terms it means, that all Members States need to ensure that cost is not a barrier to an opportunity for hard of hearing citizens.

"No one should be priced out of equal opportunity"  
We encourage all members and those who are working with hard of hearing people to support this Declaration. We are looking forward to positive contributions to the debate and to receiving your reports on the impact of the Declaration on the health policies in your countries. To see full text of Declaration and signatures, please go to [www.efhoh.org](http://www.efhoh.org). The Declaration can be downloaded on our News and Resources pages.

Lidia Best  
EFHOH Vice President

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## Hire a EFHOH **speaker!**

Invite us to talk. We can travel to your event to present and share our work and lobbying experiences.

We may present about IFHOH Human Rights Toolkit and Prague Declaration, the UN Convention on the Rights of Persons with Disabilities, including our subtitling lobbying work.

EFHOH representatives will never charge for their presentations, however we may request for travel and accommodation to be covered by the inviting party.

Please contact us at [office@efhoh.org](mailto:office@efhoh.org)

## Report from the **AEA** Mini Symposium

Last May, the AEA (Association of the European Hearing Aid Professionals) organised a Mini Symposium at the Brussels Audiology University College: Institut Libre de Marie-Haps. Several very interesting papers were presented:

The costs of untreated hearing loss has been thoroughly studied in the United Kingdom. Paul Breckell, Chief Executive at Action on Hearing Loss, presented the main results of four different reports. The path breaking one, Bridget Shield's research for Hear-It in 2006, found that unaided hearing loss in European countries costs 170bn Euro per year.

Last year, a study by the Ear Foundation estimated at 37bn euros per annum the direct costs of treating hearing loss and of dealing with the health and social impacts.

In 2011, a research report into hearing loss in the workplace by Laura Matthews for Action on Hearing Loss revealed that less than half people told their colleagues, only 37% told their employer, 14% changed jobs as a result of their hearing loss, and 36% who retired early did so directly because of their hearing loss.

In 2014, the International Longevity Centre - UK (ILC-UK) published the Final Report of the Commission on Hearing Loss. It estimates that the employment gap costs the UK economy almost 31bn euros.

Lidia Best (EFHOH) presented the end-user view on "The quality of hearing care", discussing impact of hearing loss on a person, their quality of life and how professionals can help by working together to achieve good outcomes in both hearing care and wellbeing. The person centred approach combined with good quality of fitting and after care are essential to improve satisfaction of using a hearing aid. Lidia has also stressed the importance of peer support and audiologists working together with user organisations. Additionally, Lidia spoke about austerity measures affecting access to hearing aids and why Essen Declaration was important to all. [http://media.wix.com/ugd/c2e099\\_13e3b120ba6b4518a5567ce2287cc593.pdf](http://media.wix.com/ugd/c2e099_13e3b120ba6b4518a5567ce2287cc593.pdf)

Peter Sydserff from the BSHAA (British Society of Hearing Aid Audiologists) gave a panorama of the "The UK Hearing Care Market". One striking feature is the feminisation of the profession: whereas in the 50-54 years old generation there were more than twice as much men than

women audiologists, the proportion is exactly reversed for the generation 20-29.

Søren Hougaard, from the EHIMA (European Hearing Instrument Manufacturers Association) presented some preliminary results from the EuroTrack 2015 survey. We will come back to this survey in the next issue of our newsletter when more results are available.

Dr. Husstedt, from the Deutsches Hörgesundheit Institut explained why PSAPs (Personal Amplifiers) are not listed in the "List of Aids" (Hilfsmittelverzeichnis) in Germany. He tested 4 devices with prices ranging from 10 to 30 Euros. Basically the reason is the very poor acoustic quality of these devices and the fact that they do not allow for limiting the maximum output sound pressure. Damage to the residual hearing even with a short period of wear is likely! Also, those devices are not being fitted to individual's hearing loss resulting in bad quality of listening experience.

Patrik Verheyden, from the BIAP (International Bureau for Audiophonology) BIAP stressed the need for training about hearing care for the staff in charge of older patients in care institutions. The results of his study, using simple and yet effective toolkit has proven benefits to older people and their quality of care.

According to Mark Laureyns, President AEA diabetes prevalence is expected to grow 55% in the next 20 years. This has important consequences for hearing care since diabetic patients Type 1 and Type 2 have double the chance (2.15 times more) of having hearing loss than non-diabetic people, regardless of age. Diabetes patients seem to be more susceptible to noise-induced hearing loss and this may be due to impaired recovery from noise-induced injury, the study concludes. Amplifon suggests people with diabetes should be urged to undergo follow-up screening for prompt detection of any hearing loss.

For the hearing professionals, they do need to check if patient has diabetes and adjust their hearing aids accordingly, as those patients have higher noise sensitivity issues.

The research presented is now published and available <http://www.amplifon.com/Medici%20Nes/ENG/Consensus%202014%20ENG.pdf>



## Update from the Policy Officer

For EFHOH, most of my focus for the last months has been producing a number of documents that many of you would have seen at the AGM. These were the State of Subtitling Report 2015, a policy paper on hearing loss statistics across the EU, and the Essen Declaration against cuts to hearing loss treatment, particularly state-funded hearing aids. In many ways, therefore, the AGM and conference represented the culmination of my contribution over the last six months to EFHOH's vital work.

Our State of Subtitling 2015 report is now available on the EFHOH website. This report is designed to provide a tool that can be used in any European, national or local campaigns on the issue of subtitling. There are countries and service providers that provide a good level of subtitling, so if this is not the case in your country then you should not put up with it! Access to audiovisual media through subtitling is easily achievable, and more importantly it is a fundamental right. Across the three main areas that are focussed on in the report – television, On Demand, and cinema – several themes repeatedly emerged:

- There are strong leaders and those that are lagging behind the rest.
- Data collection, or specifically a lack of data collection, means information is not as easily available as it should be.
- Legislation and regulation are essential to improving the state of subtitling in the EU.
- There is a considerable public – private gap, with the private sector generally representing one group that is lagging behind.

The issue of data collection featured prominently when I was producing a second policy paper on the issue of hearing loss statistics across the EU. The main point that

should be taken away from the data that I was able to collect is that if we are to fully understand how the issue of hearing loss affects different countries across Europe then more needs to be done with regards to standardised data gathering. Some countries collect data by a certain measure of what constitutes hearing loss, others collect data using a different measure, and many do not collect data at all. This makes it almost impossible to assess how effectively different European states are treating hearing loss and providing accessible services for those who experience hearing loss. My report just breaks the surface of what is a complex statistical issue, and one that is likely to continue to be an issue that EFHOH and Europe in general will need to address.

I am now nearing the end of my time as EFHOH's volunteer policy officer and intern at Action on Hearing Loss in the UK. This has been a fantastic experience for me, working with both organisations and having the opportunity to meet many of the members at last month's AGM and conference in Essen, Germany. Thank you for the opportunity to get to know and work with such a dynamic and diverse organisation, and I hope that I will meet you again in the future.



## VDNR (Vuxendövas Nordiska Råd) Workshop in Tallinn, Estonia 18.4.2015

Lidia Best and Jaana Linna represented EFHOH in VDNR Workshop in Tallinn on 18.4.2015. VDNR is a cooperation body, or a council, of Nordic committees of late deafened adults. The committees of late deafened adults operate under their national associations in Denmark (Høreforeningen), Finland, (Kuuloliitto = Finnish Federation of Hard of Hearing), and Norway (Hørselshemmedes Landsforbund). The Swedish organization Deafened Adults in Sweden, VIS, is an independent organization.

The goal of VDNR is to promote the rights of late deafened adults in the Nordic countries. VDNR holds official annual meetings and a seminar every year, and they organize a Nordic Summer Week every other summer. This year the summer week will take place in Norway. The webpage

of VDNR can be found here <http://www.vdnr.org/> It is in Swedish but if you click the flag of GB in the upper right corner of the front page, you will get a google translation in English.

VDNR had the annual meeting in Tallinn, Estonia this time. The Workshop was on the next day after the meeting. This was the second open VDNR workshop. The first open workshop took place in 2014 in Espoo, Finland. The Estonians attended the VDNR workshop for the first time in Espoo. VDNR wanted to expand the cooperation between late deafened groups to the Baltic area, so they had the AGM and workshop 2015 in Estonia. This was the first time the workshop was in English and it was hosted by the Estonians. Previously the language of the VDNR



The workshop day ended with an STT interpreted walking tour of the beautiful Old City of Tallinn. The Finnish STT interpreters used specially designed harnesses that enabled them to write while standing on the street (see the photo).



workshop was Swedish but it was changed to English to make the workshop accessible to the Estonians.

Lidia Best, vice president of EFHOH, gave a presentation on EFHOH. Her topic was "Promoting the interests of late deafened people at European level." The Estonians had invited several interesting speakers in addition to Lidia Best:

- An Estonian MEP, Mr. Indrek Tarand, who was introduced as the potential next president of Estonia, came to greet the workshop participants and welcomed them to Tallinn.
- Mr. Jüri Jaanson, a hard of hearing member of Estonian parliament, spoke about the situation of hard of hearing and late deafened people in Estonia. Estonia has ratified the UNCRPD in 2012. Persons with hearing loss have an improved access to education and the Estonian TV has added subtitles to socio-political programs. They also have loopsets in theatres. However, there are still many challenges like very expensive hearing aids. People need financial support from government to get the HAs. There are no STT interpreters in Estonia now, but they are planning to send two trainees to Finland in the fall to study STT interpreting.
- Mr. Meelis Joost from Estonian Chamber of Disabled People (EPIK) gave a presentation on disability policy and developments in Estonia. EPIK represents Estonia in European Disability Forum. EPIK lobbies for the rights of persons with disabilities on state level in Estonia. They participate in legislative changes via working groups. EPIK also raises awareness about disability and lobbies for equal rights for persons with disabilities.
- Mr. Sami Virtanen from Finnish Federation of Hard of Hearing (FFHOH) gave a presentation with the topic

"Subtitling – Risks and Future". FFHOH has been a member of sub-committee on accessible communication of the Finnish Ministry of Communications. The Bill on Television and Radio Operations became valid on 1 July 2011. Every TV channel has annual subtitling quotas for the years 2011 – 2016. The quality of subtitling is followed by FFHOH and Finnish Association of the Deaf. Online broadcasting and live TV-programmes are a challenge. There is no voice recognition system based on Finnish language available yet.

The workshop day ended with an STT interpreted walking tour of the beautiful Old City of Tallinn. The Finnish STT interpreters used specially designed harnesses that enabled them to write while standing on the street (see the photo).

Many thanks to our Estonian hostess, Mrs. Külliki Bode, and to the Finnish organizers, Mrs. Sari Hirvonen-Skarbö and Mr. Kalle Tervaskari, for an interesting workshop day in Tallinn!

## INSIGHTS FROM THE RESEARCH

# WHY DO PEOPLE GET **ANGRY** OR **FRUSTRATED**, WHEN YOU ASK THEM TO **REPEAT** WHAT THEY JUST SAID?

Most of us have tried this several times. We miss something, when we talk with somebody. It can be a single word or more, but it is enough to make us ask: Can you please repeat the sentence you just said! I am hard of hearing, so I did not hear what you said. Most times people do what we ask them to do and repeat the sentence. But once in a while this can result in an unexpected reaction – people get frustrated or angry for what appears to be no real reason. There are several variations of this – ranging from people getting very angry and leaving the conversation to people, which changes the wording of the sentence, so it is like they speak to a child or to people saying, it was not important and therefore not worth repeating.

It can happen in any circumstances, both with strangers and people who know us and knows we are hard of hearing. The question is – what is happening and why is it happening? And can be done something to prevent is?

If we look at any meeting, or as it is called in the social sciences, an interaction, between people, it can be noted, with reference to famous social scientist Erving Goffman, what every interaction between people contains two levels of communication. One level is about the subject – what is being talked about, e.g. the weather or the latest episode of a popular television sitcom – and the second level concerns the social level. On this level it is constantly communicated, how we evaluate each other socially. The central question is there if we see each other as trustworthy? Are we behaving as expected? This is communicated concurrently with the other level of communication.

Both levels are important. But it is important to be aware of that the second level most of the time works on an unconscious level. We are not aware of it, but it is still there and it does still have implications on our actions.





Armed with this knowledge it is possible to analyze that is happening, when we are asking them to repeat something they just said, and why they can get frustrated or angry. When we do ask someone to repeat something – we are as hard of hearing only focusing on the communicative level – on what is being said – but at the same time we are saying to that person – unconsciously – on the other level, that we are not satisfied with their communicative performance, as we were not able to understand them properly the first time around. And it is this message some people react on and gets angry because of. It is important to remember much of this does happen on an unconsciously level. We are not aware of it, but do still affect the interaction.

Another sociologist, Thomas Scheff, adds another piece to our understanding. For Scheff, the anger is connected to the feeling of shame. It is a very powerful feeling. And that is why people sometimes refuse to repeat something, saying it wasn't not important; it is because they feel it would be shame full for them repeat it, and therefore they won't do it. It is not an actual evaluation of the value or rather lack of it of the former message, but the fear of the feeling of shame, which is working here.

What can be done? Much of this happens as a result of how human interaction is structured. It is thus difficult to

avoid as a hard of hearing – misunderstandings will happen and we will have to ask people to repeat themselves from time to time. But our analysis does points to several possibilities. One is to beware of the importance to make ones surroundings aware of the hearing loss and the consequences of it. And this in a way, which makes it clear to the others that we are not questioning their communicative abilities.

This can also be done by explaining why we didn't understand it all. It could be because of noise in the background or other things. But even if we do our best, it is very likely we will experience anger or what appears to be lack of understanding. It is unavoidable and sometimes we must simply accept it as a fact of social life.

About the author: *Niels-Henrik M. Hansen is an associate professor at the department of learning and philosophy at University of Aalborg, in Copenhagen. He has an PHD in sociology from University of Copenhagen. His work is mainly focused on the life and living conditions/challenges young hard of hearing faces in their everyday life. He is former president of IFHOHYP and is currently editor of the EFHOH Newsletter. He has a severe hearing loss and suffers from Ushers, type II.*

Contact: [nmh@learning.aau.dk](mailto:nmh@learning.aau.dk).



## EU EQUAL TREATMENT LAW: THE TIME IS NOW!

Brussels, 18 June 2015 – six months ago, organisations representing millions of EU citizens at risk of discrimination called on EU Member States to show clear commitment on the proposed Horizontal Directive on equal treatment. In the meantime, some progress has been made and the Directive should now be adopted without further delay. Equality for All wants to debunk the lingering excuses that are still used by some Member States and remind that there are still millions of people in the EU suffering daily from preventable discrimination.

In 2008, the Commission proposed to complete EU legislation on equal treatment. Seven years later, the proposed Directive is still stuck in negotiations, due to strong resistance from a few Member States. This is unacceptable, as fundamental rights are not up for negotiation or cherry picking. We all deserve equality, and the Directive is key to making that happen.

In the annexed paper, we debunk the main excuses that we still hear from Member States:

- The 'subsidiarity' argument completely overlooks the fact that similar legislation covering racial and gender equality already exists.
- The 'burden on Member States' argument is totally invalid, particularly now that the scope and implementation period of the directive have been amended in the latest text.
- The 'too costly' argument is incompatible with existing human rights obligations and ignores the numerous economic gains that will be made.

The Directive is needed to tackle the daily discrimination experienced by many people across the EU:

- Discrimination and bullying at school, leading to stigmatisation, social exclusion, dropping out of school and even to elevated suicide rates.
- Denying same-sex couples basic rights, such as the right to visit his or her partner in the hospital or to sleep together when on holiday in a hotel.
- People with disabilities not being given essential information in accessible formats when treated in hospital.
- The refusal of insurance policies to cover elderly people and people with disabilities, including even children with disabilities.

Equality for All again urges all EU governments to show unanimous leadership and adopt a strong anti-discrimination Directive protecting all people in their daily lives as soon as possible!

## EUROPEAN PARLIAMENT ADOPTS RESOLUTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Yesterday the European Parliament adopted a resolution in which it expresses its strong support to the full implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD). It was adopted with an overwhelming majority among the political parties.

The resolution followed a plenary debate of the European Parliament and a public hearing, in which MEPs and representatives from the disability movement and EU institu-

tions discussed the state of play of the implementation of the UN Convention.

The resolution states that the European Parliament should be fully involved in monitoring and implementing the UN Convention. In particular it highlights the UN Convention review process and the constructive dialogue between the EU and the UN CRPD Committee.

EDF welcomes the European Parliament's resolution and its involvement in the review process. We believe that the EU institution representing 500 million EU citizens should be on an equal footing with other EU institutions in designing EU laws and policies for persons with disabilities.

Through its resolution, the European Parliament supports the adoption of two key pieces of legislation: the European Accessibility Act and the General Antidiscrimination Directive; both pieces of legislation are essential part of implementing the UN Convention.

The resolution also calls on the Member States to translate the obligations derived from Article 12 of the UN Convention into national laws and most specifically, the right of all persons with disabilities to vote and to be elected.

As a party to the UN Convention, the EU should also ensure that all its external actions foster the inclusion and participation of persons with disabilities through their representative organisations. However, some policies, such as the Gender Action Plan, did not include specific references to persons with disabilities.

## THE EU MONITORING FRAMEWORK RENEWED ITS COMMITMENT TO PROMOTE THE UN CONVENTION

On 4 March 2015, a high-level meeting of the EU Monitoring Framework on the UN Convention on the Rights of Persons with Disabilities took place. The European Commission, Members of the European Parliament, the European Ombudsman, the European Union Agency for Fundamental Rights and the European Disability Forum renewed their commitment to promote, protect and monitor the rights of persons with disabilities in the EU in line with the UN Convention.

The meeting comes ahead of important developments. In particular, in 2015 the UN Committee in Geneva will review the progress of the EU in implementing the UN Convention and the Framework will actively participate in this process. EDF is there to ensure the voice of persons with disabilities is heard in the work of the Framework, including with regards to the review process.

## THE DISABILITY INTERGROUP DISCUSSED ITS PRIORITIES

The new, larger, Bureau of the European Parliament Disability Intergroup met for the first time at the end of February. In particular, MEPs discussed work priorities for 2015-2016.

EDF worked to ensure that the intergroup objectives are close to our priorities, as set out in EDF work programme 2015: UN CRPD EU review by the UN Committee; equal access to transport and to goods and services (European Accessibility Act, European disability card); antidiscrimination directive; revision of the European Disability Strategy; revision of the Europe 2020, European Semester and employment issues; Digital Single Market; international cooperation and post-2015 development framework; independent living and de-institutionalisation; accessibility of the European Parliament meetings, communication and processes.

There was strong sense within the Bureau of the need to strengthen the role of the intergroup as a forum for dialogue with the whole disability movement.

The provisional list of Disability Intergroup MEPs can be found at [www.disabilityintergroup.eu](http://www.disabilityintergroup.eu).

A record number of MEPs – more than 110 – have joined the intergroup so far!

## COMMISSIONER THYSSEN COMMITS TO SUPPORT THE RIGHTS OF PERSONS WITH DISABILITIES

On 20 April 2015, EDF and the Belgian Disability Forum (BDF) met Commissioner Marianne Thyssen to discuss the EU's responsibilities towards persons with disabilities.

In the beginning of the meeting, BDF President, Pierre Gyselinck, underlined that EDF is representing 80 million citizens with disabilities across Europe; therefore the EU has the responsibility to take actions towards their full inclusion.

During the meeting, EDF and BDF stressed the importance of the implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD) by the EU, calling for robust mechanisms to implement the UN CRPD, with the necessary financial and political support.

We also called for the adoption of an ambitious European Accessibility Act: "The promise of accessible goods and services for persons with disabilities has been delayed for too long now. We urge the Commission to make the European Accessibility Act a priority, and most importantly to

consult persons with disabilities on the legislative text. Till now persons with disabilities have not been consulted; this is in direct conflict with the UN CRPD”, said EDF President, Yannis Vardakastanis.

Commissioner Thyssen said that providing citizens with disabilities with equal access to goods and services across the EU is not just a priority, but also an obligation that the Commission will fulfill in consultation with organisations of persons with disabilities.

BDF stressed the necessity of the adoption of a European Mobility Card: “It’s a concrete step to ensure that persons with disabilities enjoy freedom of movement on an equal basis with others”, said BDF General Secretary, Gisèle Marlière. Freedom of movement for persons with disabilities is a long standing concern of EDF: ‘All new measures the EU put in place, for example the Labour Mobility Package, or existing programmes, such as Erasmus, need to fully include person with disabilities’ added EDF Director, Catherine Naughton.

EDF and BDF underlined that the European Semester process should include recommendations which lead to proper implementation and monitoring of European Funds and should promote investments towards independent living and employment for persons with disabilities.

Commissioner Thyssen recognized also that the revision of the European Disability Strategy comes at an ideal time; the EU will receive concluding observations from the UN expert Committee on the CRPD, and will be able to use the upcoming Disability Action Plan as a means for implementing them.

The review of the Europe 2020 Strategy also provides an opportunity to promote the rights of persons with disabilities. At the same time, Commissioner Thyssen emphasised that the fight against poverty and discrimination is on top of the Commissions agenda. She said that we should join forces to achieve the goal of a society where people are not left behind.

EDF and BDF welcome Commissioner Thyssen’s invitation and are determined to work closely towards this aim.

## LATVIAN EU PRESIDENCY HOLDS MINISTERIAL MEETING ON THE IMPLEMENTATION OF THE UN CONVENTION IN THE EU

EDF urges for regular ministerial meetings on the rights of persons with disabilities

Today in Riga, the Latvian Presidency of the EU organised a High level Meeting on Disability focusing on inclusive

education and inclusive employment of persons with disabilities. During the meeting, a ministerial discussion took place in order to identify accomplishments resulted from the UN Convention on the Rights of Persons with Disabilities (CRPD) in the EU and the challenges ahead. EDF and its members are present in Riga to contribute to the discussion and express the views of persons with disabilities.

The aim of the ministerial discussion was to identify the achievements and challenges that member states have to overcome to move towards a Europe free from barriers and obstacles. The meeting also targeted to define which measures at EU level have successfully supplemented endeavours by member states and need to be improved in the future.

Although education is one of the main preconditions for employment quality, inclusive education for persons with disabilities is still far from being a reality. “Young people across Europe face phenomenal levels of unemployment, and young people with disabilities are much more likely to be unemployed. Exclusion from the labour market is growing. Access to decent work within the EU is decreasing. Education services are under resourced and are not inclusive. Vocational training as a preparation for the labour market is not available to the majority of persons with disabilities”, said EDF President, Yannis Vardakastanis.

EDF President also expressed the hope of the disability movement that the upcoming Presidencies of the EU Council will follow the good example of the Latvian Presidency and will organise regular ministerial meetings on the rights of persons with disabilities. This is essential to ensure a coordinated approach from the EU institutions and member states all of whom have signed the UN Convention.

“This is the year that the UN Committee will review the work that the EU has done to implement the UN Convention. The Concluding Observations of the UN Committee will be adopted on 3 September 2015 and should be high on the agenda of the next EU Presidency since they will serve as a basis for disability policy in the EU and at Member State level for the coming months and years”, emphasised Yannis Vardakastanis.

80 million persons with disabilities in Europe expect that the EU will take important steps this year to fulfil their commitment to the UN Convention. The EU is expected to adopt comprehensive anti-discrimination legislation and the European Accessibility Act. These pieces of legislation are critical for the access of European women, men and children with disabilities to schools and work.



## EFHOH MEETINGS 2015 & 2016:

<b>2015</b>	<b>2015</b>	<b>2015</b>	<b>2015</b>
28 March	Antwerpen / Belgium	Symposium 60 years Onder Ons	Marcel
9 April	Essen / Germany	IFHOH board meeting	Marcel
10-12 April	Essen / Germany	EFHOH Annual General Meeting (AGM)	All EFHOH board members
18 April	Tallin/Estonia	Nordic Late Deafened Conference	Lidia and Jaana
17 May	Brussels	AEA AGM/Symposium	Lidia and Marcel
29-31 May	Warsaw/Poland	EDF AGA	Lidia and Marcel
25-27 September	Athens/Greece	Hearing Awareness workshop + board meeting	All board members
22-23 October	Copenhagen	Human Rights Train the Trainers training	All board members
3 December	Brussels	European Day of Disabled People	One of the board members
<b>2016</b>	<b>2016</b>	<b>2016</b>	<b>2016</b>
1-3 April	Paris / France	EFHOH AGM	All EFHOH board members
23-26 June	Washington DC /USA	IFHOH BGM and world congress	Marcel

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## EFHOH - European Federation of Hard of Hearing People

The European Federation of Hard of Hearing People consists of National Associations of/for Hard of Hearing and Late-Deafened People, Parents' Organisations and Professional Organisations.

EFHOH comprises the European members of the International Federation of Hard of Hearing People (IFHOH) and was established in 1993. It has its own board and secretariat. The federation has non-profitable and benevolent aims and it is a non-political and non-sectarian organisation. EFHOH is a general member of the European Disability Forum (EDF). We also work in good co-operation with IFHOH and our official language is English.

The Board members of the EFHOH carry out their work on an honorary basis.