EFHOH

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

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President letter
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European Federation of Hard of Hearing People



EFHOH PRESIDENT LETTER

By Marcel Bodeldijk

Dear EFHOH Members and Newsletter Readers, Warm greetings from the EFHOH board! November is coming to an end and December is approaching fast, in other words, the last busy weeks of the year are coming up. For us as the EFHOH board, 2019 was an interesting year with many inspirational meetings and events.

Some weeks ago, after the first day of the Kentalis conference (https://www.kentalis.nl) in Haarlem, Aïda and I along with Bryan (EFHOH webmaster) and Wendelina Timmerman (Hooridee) choose not to go to a restaurant as we had concerns about background noise. We made the choice to have some take away food and have our dinner in Wen-

delina's office which was a great success because we now had the possibility to have a stress-free conversation without the difficulties in hearing or understanding the topics. I highly recommend quiet dinners without background noise so that you may enjoy your meal as well as the conversations.

In this EFHOH newsletter, we have some news about the different events that EFHOH board members participated in. And, of course, also some news from IFHOH and their upcoming World Congress in Budapest. We hope to see all of you in Budapest. Please make a note in your planner that the EFHOH AGM is on Wednesday 27 May (the day before the IFHOH World Congress).

On 9th November, I and some HoH friends from Finland participated in the EDF/EU seminar regarding the Accessibility of Transport and Built Environment for Persons with Disabilities. You can find the resolution on our website: https://efhoh.org/news-fromefhoh.

We hope to send to our members the new EDF Toolkit about Audiovisual Media Services Directive (AVMSD) soon. This revised AVMSD was adopted in November 2018 and presented an opportunity for member states to advance media accessibility and protection of consumers against discrimination and hate speech. Member states now must transpose the directive into national law by 19th September 2020 and communicate the text of this provision to the European Commission. By transposing, we mean to reform or adopt national laws to comply with the EU directive.

I hope that you have a nice winter holiday and a wonderful Christmas with your friends and family. For the EFHOH board it is also a good moment to say thank you for your support in 2019. We hope that you will also support us in 2020 with your articles for the EFHOH newsletter, your ideas, and financial support.

News on the EFHOH Website:

We hope that you continue to visit the EFHOH website: www.efhoh.org especially News as we have various and interesting news to share. Also, it is recommended that you check for updates regarding the IFHOH World Congress in Budapest.

CALL FOR ARTICLES FOR THE NEXT EFHOH NEWS-LETTER:

If you have an article for one of the next EFHOH newsletters in 2020, please send it to us at: info@ efhoh.org

SAVE THE DATE:

- 4th March Lunch Debate in the European Parliament in Brussels
- EFHOH AGM 27 May 2020
- IFHOH world congress 28-29 May 2020: https:// efhoh.org/ifhoh-world-congress-2020

Dear All,

On behalf of the EFHOH board, I wish you all, together with your family and friends, a Merry Christmas and a Happy and Successful 2020! I hope to see you all in Budapest.

Warm Regards, Marcel Bobeldijk



Make New Memories: **Attend Congress 2020**

Do you remember your first IFHOH Congress? I hope that you have had the opportunity to remember one, but if not, you can sign up for your first Congress May 27-29, 2020 in Budapest, Hungary.

For those of you who do remember a Congress, I wonder what stands out most for you? Is it

- Attending an inspiring presentation
- Having a scintillating conversation with another delegate
- Enjoying the atmosphere of a new place
- Or. Just All of It!

IFHOH 2020 World Congress in Hungary



For me, it is probably Just All of It. But the journey for my first IFHOH Congress was the most memorable. It was in 1984 and our Canadian Association had received air tickets for me to attend the Congress. The air ticket was to the closest airport destination to the Congress, which was Frankfurt. From there I took a train through Germany and Denmark to Sweden to the final destination of Stockholm. A complete stranger on the train befriended me and invited me to stay the first night with her while I got my bearings. After the Congress, I retraced my journey and was kindly invited by then General Secretary of IFHOH, Hannelore Hartmann, to stop over in Hamburg. Her and her husband took me on a tour of the city. Nowadays I am likely to fly direct but there is something to be said for having a more meandering journey.

Whether you come by airline, train, bus, boat or car, please do make the 2020 Congress your must-attend event for next year. SINOSZ, our partner, has been working hard on putting together this event with IFHOH, and information is available on the website about registration and the Call for Papers. Please go to https://www.ifhoh2020budapest.com/. Dr. Laszlo Lovaszy, Ph.D, from Hungary who is a member of the UN Committee Rights of Persons with Disabilities, and Dr. Shelly Chadha, technical officer for the World Health Organization, will be keynote speakers.

The EFHOH AGM and IFHOH BGM will be held on the first day of the Congress, following an evening reception. After two days of presentations, a gala dinner will close the Congress, leaving the weekend free to sightsee and enjoy other pursuits.

Two important deadlines are:

15 December – oral and poster presentation submission deadline

15 January – early bird registration deadline

So I look forward to seeing you in Budapest to make new memories.

With best regards, Ruth Warick, President, International Federation of Hard of Hearing People (IFHOH)



Hearing Loss and dementia

On 4th of October Danish Association hosted a conference on the topic: "Hearing Loss and Dementia" at the Centre for Hearing Loss in Fredericia, Denmark.

Am I developing dementia? Or am I just facing difficulties in hearing? Is there a connection between hearing loss and dementia?

This was the topic, when Danish Association of Hard of Hearing facilitated a conference at the Centre for Hearing Loss in Fredericia.

Every year around 7.700 Danes are diagnosed with dementia, and it is estimated that around 80.000 Danes have this diagnosis. In this population only around 1500 are younger than 65 years old. Therefore, it stands quite clear, that the risk of developing dementia increases with age. At the same time, it is far from all elderly people who

At the same time, it is far from all elderly people who develop dementia.

To understand how hearing loss relates to developing dementia, it becomes important to understand, what is in fact dementia, explained hearing Consultant and Educational Audiologist, Heidie List.

Dementia is not just one disease, it is something that follows a long row of other diseases and illnesses.

- Causes of dementia are many and very different.

However, the symptoms usually appear as some kind of problems with one's memory. Suddenly it is not so easy to remember, one becomes slow in reaction to some command, cannot find his way, is searching for words or names, she said.

Dementia appears, when some nerves in the brain no longer function sufficiently. More precisely, the nerve cell connections between different areas of the brain degenerate.

This can be shown in an MR-scanning. Both short time memory and long term memory can be affected by dementia.



Short time memory we typically use to handle the things, we work on here and now and to remember a message. Long term memory holds our learned and built up knowledge about the World as well as our remembrance of what has happened and the things we have learned, eg how to ride a bicycle, make coffee, take a shower etc.

When we speak, we use both short time memory and long term memory. We need to keep track of both: what we are talking about, what has been said previously in this conversation and how to contribute to the conversation.

The important nerves

Hearing loss is caused by a defect somewhere in the hearing system. It causes that a sound signal, which is received via our ears, is defect [out of tune, AR], when it reaches the auditory brain. In other words, we hear with our brain, the ears are only transmitting the sound signal to the auditory brain, where we process and understand the sound.

For instance we use our hearing to contact and communicate with others, and if the hearing is damaged, it may result in isolation, loneliness and depression. Fortunately, we do not orient ourselves solely through language and sound.

Body language and mimics mean just as much.
- Research has shown, that people with typical hearing use about 5 % of their energy to listen, while

people with tinnitus and hearing loss use 25 %, and those with severe hearing loss use up around 50 %. This explains, why people with hearing loss are easily tired out by being among others and orient themselves and sort out what is being said and going on, said Heidie List.

If you do not get your hearing aid in time, other centres of the brain will take over, eg senses of sight and touch. In this case the auditory brain is not being stimulated enough, and it becomes harder to re-activate it.

If, on the contrary, you have a hearing aid or a cochlear implant in due time, there is a chance, that the nerves to auditory brain will not become completely inactive. The older you are, the more difficult it is to recover the nerves.

- Many HA-users report that they do not use their HAs, when they are on their own, because then there is no conversation. But everyday sounds as bird song, the humming of the washing machine, the winds etc are all sounds that stimulate the brain, preserve nerve pathways and keep the auditory brain active, she added.

Newest research

Chief Physician, Clinical Lector in Audiology and Ph.D., Jesper Hvass Schmidt, had also been invited to



Participants.
Carsten Dauggaard (hearing engineer) and Maibritt Frisch (CFD).

this conference. In 2018 he started a research project on hearing loss and dementia from the University Hospital in Odense, Denmark.

- -The occurrence of dementia grows remarkably with elderly people who have hearing loss.
 Still we do not know, if the risk of developing dementia is bigger for people with hearing loss.
 But, in any case a healthy old age does help to prevent developing dementia, he explained.
 Research suggests, that risk of dementia is lower among higher educated population, he said.
 A creative craftsman, who uses his brain a lot, is likely to also have less risk of developing dementia. In all cases it can be concluded, that it is important to stay active both socially, mentally and physically.
- The most common signs of dementia are problems with memory, slow reaction and cognitive decline, meaning that one forgets, how daily routines should be carried out. The difficult thing is, that these symptoms can also be caused by reduced hearing. In this case it becomes quite natural to ask yourself: Am I developing dementia? Or am I facing difficulties in hearing?

This is still not quite clear, but Jesper Hvass Schmidt does recognise a link between hearing loss and dementia. And still, it cannot be proved that it helps

to use hearing aids, but it is likely, that they can help preventing or postpone the development of dementia. Up until now, Jesper Hvass Schmidt concludes, that hearing loss is a risk factor in line with many other illnesses. And that the bigger hearing loss, the bigger risk.

When there are more elderly people who are diagnosed with dementia, it may be related to the quite natural loss of senses with age. This is not just related to loss of hearing but also vision, balance and motor control. It is likely to assume that all these factors increase the risk of dementia.

In fact, Jesper Hvass Schmidt stated that there is no direct cause, that hearing loss causes dementia – he would cross that out with a big, fat, red pen.

His best advice is to look to the hearing loss as giving up smoking: It is better to intervene in due time, since the consequences of an untreated hearing loss is likely to be more difficult than those from an audiological treated hearing loss.

Is untreated Hearing Loss worse?

The key issue during the debate, that followed, was: Is there a bigger risk of developing dementia, if you

Hearing loss and dementia in numbers:

- Out of 800.000 with some kind of hearing loss in Denmark, around 300.000 use HAs.
- In USA 3,8 millions out of 26 millions with hearing loss use HAs.
- Untreated hearing loss in Europe cost 213 € annually
- Dementia is the biggest functional disorder worldwide, it is estimated that right now there are 24,3 millions with dementia
- Dementia accounts for 11,2 % of all life years with a disablitly, whereas apoplexia only accounts for 9,5 %, cardiovascular diseases for 5 % and cancer for 2 %.

Causes of dementia:

Alzheimer's disease 62 % Vascular diseases (stroke, atherosclerosis) 17 % Mixed Alzheimer's and Vascular dementia 10 % Lewy body dementia 4 % Frontotemporal dementia 2 % Parkinson's disease 2 % Other reasons, eg head traumas 3 %

How to prevent dementia:

Have a healthy old age
Be physically active
Avoid injuries, in particular in your head
Use your brain
Be social and interact with other people
Consult your doctor in due time

live with an untreated hearing loss? Often, HoH people seem confused and speak suddenly about totally different topics. But is this then a sign of the onset of dementia?

It need not be, said Jesper Hvass Schmidt. We still do not know, to what degree hearing aids and cochlear implants can prevent dementia – if at all, was the answer.

One in the audience asked, if those who have been born deaf or with severely hearing loss face bigger risk of developing dementia? Heidie List reassured that in that case the areas of vision in the brain would take over the auditory brain's functions, and no higher occurrence of dementia has been detected in this population.

Hanne Friberg from Danish National Center for Dementia commented that dementia is always best prevented by being socially active. Research also suggests that regular exercise can be a contributing factor in preventing development of dementia. In this case it is important to keep both your body and your brain activated.

Aïda Regel Poulsen from Centre for Hearing Loss (EFHOH secretary) rounded off the conference by suggesting, that the mental effort it is to have a hearing loss, may cause a higher level of stress, and that there might be a connection between stress and dementia, which also raises the question of the necessity of accessibility for HoH people in society. This is all something we shall become much wiser on in the years to come, thanks in part to Jesper Hvass Schmidt's research project.

This article on Hearing Loss and dementia has been translated into English from an article in Danish members' magazine "Hørelsen".

Author of the article is Kirsten Winding. Photographer is Palle Peter Skov.The article has been translated and adapted by EFHOH secretary, Aïda Regel Poulsen.

LTA project news

This is the LiveTextAccess (LTA: http://ltaproject.eu) project mailing list.

We have started the newsletter to keep you inform about the LTA progress. You have been included in the list because you have been in contact with us.

We are glad to inform you that:

- Intellectual Output 1 is finished: https://ltaproject. eu/?page_id=101
- You can find these two reports on Intellectual Output 1 on the page:
- o Skills and competences of the professional
- o Training practices in real-time intralingual subtitles

LTA event in March 2019. You can find:

- o The event presentations and pictures under: Events-→2019 – Munich – Germany.
- You can watch the event videos at our You-Tube channel: https://www.youtube.com/channel/ UCW4Tp6hLEG8dty1KJTNMP0Q?view_as=subscriber

We will be at the Intersteno Conference in Cagliari on 16 July 2019. We will discuss with professionals the curriculum design and how to make it accessible for professionals.

Above all, we would like to thank for your support and your input. Please keep on following us:

- on Facebook (https://www.facebook.com/LTA-2171137243107967/),
- Twitter (@LTA_EUproject), and
- YouTube (https://www.youtube.com/channel/ UCW4Tp6hLEG8dty1KJTNMP0Q?view_as=subscriber)

We wish you a very pleasant day.

Best, The LTA team

EDF Toolkit on AVMSD

Please find attached link to EDF Toolkit on AVMSD.

https://efhoh.org/news-from-efhoh/

The Audiovisual Media Services Directive 1 or AVMSD (referred to as the Directive throughout this text) was adopted on 14 November 2018. In this section of the toolkit we give a brief introduction of the Directive with key definitions, provide a timeline for transposition and implementation, and indicate who the key players of the process are. We will also explain that it is a 'minimum harmonisation' Directive and what this means in practice. 1. Introduction The Directive creates an EU-level framework to coordinate national legislation on all audiovisual media, both traditional TV broadcasts and on-demand services (for example, Netflix, Amazon Video, Now TV). It sets out requirements concerning aspects such as prohibition of hate speech and discrimination based on disability and other grounds, commercial information on TV programs, protection of minors, independence of the national regulatory bodies that monitor audiovisual services, and the promotion of European audiovisual productions2.

Aïda Regel Poulsen EFHOHsecretary@gmail.com

New Passwords

We are pleased to inform you, that we are now at a point where we have been able to set up new Password for Members Only at the www. efhoh.org website.

Password will be changed now annually. When you enter Members Only on our website, you will find the nomination letter from Nomination Committee.

Please pay attention to that. EFHOH Vicepresident and Board Member are up for election at the EFHOH AGM in Budapest 2020.

Aïda Regel Poulsen EFHOHsecretary@gmail.com

EDF Board meeting in Helsinki:

EDF Board meeting took place on the 8 and 9 November in Helsinki, Finland. Representatives of the European Disability movement also had the opportunity to meet with Finnish Prime Minister Antti Rinne on Friday, 7 November.

The EDF board and the EU conference preceding it gathered 132 delegates from the disability movement across Europe.

Before the EDF board meeting, we held the "Seminar on accessibility of transport and built environment for persons with disabilities". The seminar concluded

with a resolution which highlights important next steps to effectively promote accessibility in Europe. EDF have also the pleasure to welcome two new associate members: Sightsavers and AGILE - the National Council of Persons with Disabilities of Switzerland.

Read the outcomes of the board to know more

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With 60 years' experience and more than 5,700 specialist centres in 20 countries, we're the world's leading dedicated hearing aid specialist.

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Hire an 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



Aïda Regel Poulsen (right) and Sami Virtanen (left) from Finland (see his article on page 14 on the same conference.

Access to Media for people with Hearing Loss

By Aïda Regel Poulsen

Presentation given at Media 4 All 8, Stockholm, June 17th – 19th 2019.

European Federation of Hard of Hearing – EFHOH – represents 52+million hard of hearing people at the European level in dialogue with European authorities. We campaign for equal rights for people with hearing loss at the European level.

EFHOH members are national organisations of/for hard of hearing people, including people with tinnitus, CI, hyperacusis, Menière's disease and deafened people.

EFHOH has previously carried out surveys on Accessibility to Medias in 2011 and 2015. www.efhoh.org Both surveys refer to UN CRPD with access to information stated as a human right.

There has been developments during these last eight years, but we are not there yet.

In particular the transmitting technology is causing delay in live subtitling.

For Hard of Hearing people we also experience delay in different types of assistive listening devices (FM, streaming) and with delay in live subtitling as well we get our information in many different speeds, which makes it difficult to administer in our brains.

In 2019 EFHOH carries out the 3rd survey on Accessibility to Medias.

For the 10 countries who have responded we see that subtitling is not 100 % yet in any of these countries. There are more responses to be received by EFHOH. When asked how much delay is accepted, in 9 out of 10 countries this was not defined. There was found lack of legislation as to subtitling on-demand in 8 out of 10 countries. Also in 8 out of 10 countries there was no legislation/regulation on subtitling on films in cinemas.- the same goes for theatres.

The positive development since 2011 and 2015 is, that accuracy in the subtitling has bigger focus now, and subtitling provision is raising – in particular in public channels.

Standards are needed to meet our human right to get information.

In the presentation Audiovisual Media Services Directive - AMSD was presented as part of the EAA (European Accessibility Act). http://www.edf-feph.org/newsroom/news/ edf-toolkit-web-accessibility-directive

EFHOH is a partner in LTA (Live Text Access) project, which is an EU funded project that tackles the current need of an open-source certified training program.

EFHOH has, since 2016, participated in the work of International Telecommunitation Union (ITU).

EFHOH works together with European Disability Forum (EDF) expert groups where we review standards and directives that reflect the needs of hard of hearing people.

Our rights - UN CRPD - become others' responsibilities. How can we work on this? Do those in charge want this responsibility?

We need better standards:

-Universal Design in assistive listening systems (ALS) as well as in access to subtitling/STT. -typing techniques (education of STTIs at University level) -hardware/techniqual functioning - connections

-frequencies/no interference

-possible delays must match between ALS and STT -Employment of HoH at TV-stations (hearing loss is a

-Accessible society

The presentation was given by: **EFHOH** secretary Aïda Regel Poulsen

We4Authors Workshop

The We4Authors workshop was organized in collaboration between EDF and Funka on the 15th of October at the Microsoft Center in Brussels. We4Authors is an EU-funded research project lead by Funka, partnering with CTIC. EFHOH President Marcel Bobeldijk and EFHOH Webmaster Bryan Bong participated and contributed to this research project. The focus was on the most popular authoring tools in the public sector throughout the EU and the accessibility features and support for web authors to comply with the Web Accessibility Directive.

The "Welcome" video message from MEP - Adám Kósa, as well as the videos and captioning transcript from the workshop with end-users, are published on the project website:

https://www.funka.com/en/projekt/we4authors/ what-is-we4authors/workshops/

Benchmark example: **Reflections** and **development** of **subtitling service** in Finland 2011 – 2019.

By Sami Virtanen

Media4all8, Stockholm, 17th – 19th June 2019

Finland has advanced subtitle legislation in EU that affects simultaneously the public broadcasting companies and the largest commercial TV broadcasters. In Finland, since 2011, there has been an Act that is regulating subtitling for TV programs. EU Audiovisual Media Services Directive and NGO advocacy work have affected greatly for the national implementation. This Act concerned in first phase one Finnish Broadcasting Company and three commercial tv broadcasters. Commercial tv broadcasters resisted in 2010 added obligations but luckily arguements on equility principles in communications were stronger

Finnish Act on e-Communications services was updated in summer 2018 and the obligations for broadcasters expanded. At same time, current increased supply of subtitled program offers better choices for hard of hearing (HOH) viewers but otherwise some measures create obstacles and limitations in distribution channels for HOH viewers.

For example the Finnish commercial tv broadcaster, Channel Four, has started to broadcast Finnish speaking programs with speech recognition subtitling. Based on feedback from HOH viewers, quality is poor. Subtitling itself might be accessible but access to have subtitling services aren't yet fully designed with user-centered approach.

Now the Finnish Ministry of Communication and Transportation has started updating Act on e-Communications services regulation at the beginning of 2019. Reason is to transpose new EU Audiovisual Media Services Directive and its 'demands. According to Ministry, a new Act on will be confirmed in summer or autumn 2020 after approval of the Finnish House

of Parliament. Autumn 2020 will send the first dratf of Act and next winter 2020 Finnish House of Parliament will dealt with Act. '

Naturally FFHOH has made active lobby work having better Act with many improvement suggestions, like demands to set up quality demand on subtitling in Act.

Presentation reflected development of legislation and subtitling covering percentages. Presentation highlighted concretely how the current digital solutions make production of subtitles easier, how tv broadcasting distribution channels and their offerings affect for HOHTV viewers. Challenges are still remaining in:

- Live subtitling, finding common operation production method and inform available of subtitling services.
- Future tv sets, how accessibility features will be supported.
- Accessibility and subtitling in Finnish broadcasters's video on demand services etc.

The aim of the presentation was to provide general description and to increase understanding of the context in which the legislation has evolved and how the increased subtitling services have contributed to HOHTV viewers.

#Finland #subtitling #digitalisation #legislation #hardofhearing #benchmarking



A British Audiologist has been rewarded for her outstanding dedication to patient care with a prestigious European hearing industry award.

Paula Cook of Aston Hearing in Amersham has been awarded the title of European Audiologist of the Year 2019, just weeks after being crowned the United Kingdom Audiologist of the Year. Paula beat finalists from France, Germany, Spain, the Netherlands and the Republic of Ireland for the coveted title, impress ing judges with her dedication to going above and beyond in her patient care.

Now in its twelfth year, the competition is organised by RAYOVAC®, a world-leading hearing aid battery manufacturer, in partnership with Audio Infos, a leading international hearing publication for the audiology industry, the European Hearing Instrument

anufacturers Association (EHIMA) and the European Federation of Hard of Hearing People (EFHOH). Other country winners who were in the running for the European title were:

- France Natacha Chetritt-Bonneyrat
- Spain Laura Girón Mairal
- Germany Jens Warnecke
- Netherlands Mariëlle de Heer
- Republic of Ireland Peter Maguire

or updates on next year's Audiologist of the Year competition visit www.audiologistoftheyear.eu like the Audiologist of the Year on Facebook on www. facebook.com/AudiologistoftheYear or follow us on Twitter at www.twitter.com/AOTY_EU.

Link to article here: http://www.audiologistoftheyear.



Kentalis congress **Teaching** Deaf **Learners**

Kentalis congress Teaching Deaf Learners, Haarlem the Netherlands: EFHOH was represented at this congress by Aïda and Marcel:

Kentalis is proud to look back on the 3rd edition of the Teaching Deaf Learners congress. We have received many positive responses to the content and organization of this congress. The congress attracted around 250 participants from more than 30 different countries. The speakers also came from various corners of the world.

Look behind the scenes

The congress started with a 'pre-conference tour' on 6th November. Participants took a look behind the scenes at Kentalis . The visit was very impressed about the education and care at Kentalis .

Scientific research in education of deaf and hard of hearing students

"Teaching deaf and hard of hearing students is not the same as teaching students who hear". This was the starting point during the two conference days. Harry Knoors opened the congress with a short video. This clearly demonstrated the importance of the close cooperation between research and practice in education at Kentalis. The video is partly in spoken Dutch, partly in sign language of the Netherlands and has English captions.

Teaching deaf and hard of hearing refugees

A special theme this year is the 'perspective from non-Western countries'. For example, there are more and more hearing impaired and deaf refugee and migrant children in the Netherlands who are being taught. The parents and sometimes the children themselves come from non-Western countries. Precisely at this point it is good to know how deafness, upbringing and education are viewed in these countries and what the countries can learn from each other. Speakers from Kenya, Chile, Sri Lanka and Jordan shared their insights and experiences.

Discussion and networking

New to the congress was the possibility to give a poster presentation yourself. The poster presentations were well attended during the breaks; there was much discussion and networking. Young people from the TOS factory took pictures on Thursday for a good impression of the atmosphere.

EFHOH overall impression

It became very clear during the conference how it is really not enough to work specifically on spelling, grammar and phonetics in language, all mainly bottom up strategies.

It is just as important to work top down on what is the topic, what do people think, what is their opinion, and that interaction with others and social communication is a basis for learning.

It was also stated many times, that sign language is not dangerous but can support learning of theory of mind (what other people think), can support what hard of hearing people are listening for, can support top down learning. But not all benefit from the same approach.

There was an interesting presentation on identity and deafness which showed a much wider range of different identities within deafness than the stereotype orally speaking >< sign language users' identity, and on the second day there were presentations showing how text and subtitling (and speech to text) can support language learning in deaf and hard of hearing population. This was at the same time beautifully demonstrated by the available STT by Velotypist Wim Gerbecks.

Accessible congress:

The congress was beautifully accessible for deaf and hard of hearing audience with sign language interpreters in both Dutch and International languages, Speech To Text in English and a well functioning loop system.

During registration it was possible to tick the boxes on what kind of accessibility one needed.



Apple Accessibility Workshop

Our administrative assistant and webmaster Bryan Bong represented EFHOH at a closed workshop on the 25th of September in Brussels. The workshop was hosted by Apple and featured Apple's Director of Global Accessibility Policy & Initiatives Sarah Herlinger. Representatives from EDF, EUD, and EASPD were also present.

During the workshop, Sarah highlighted the latest accessibility features in iOS 13 and macOS Catalina operating systems and emphasized Apple's commitment to accessibility. New features that are of interest to the hard of hearing community include a Noise App that can test the decibel levels around you in order to help you identify levels that could negatively impact your hearing.

Apple will also be launching a new streaming service that will offer original programming on its Apple TV Plus (stylized as Apple TV +) platform. Original programs streamed on Apple TV+ will include subtitles for the deaf and hard of hearing (SDH) or closed captions.

Visit https://www.apple.com/accessibility/iphone/hearing/ to see the newest and latest features for the hard of hearing.

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Image credit: WHO

On 14 February 2019, World Health Organisation HQ in Geneva was a witness to a truly remarkable moment in history. The building main foyer rocked with great sound quality but at safe loudness levels to a live concert by Ricky Kej, just few steps away from the first inaugural meeting on 1st October 2015 where ITU and WHO together with international experts in audiology, engineers, manufacturers, academics and civil society representatives have agreed on steps to tackle rising hearing loss resulting from unsafe exposure to loud music.

The concert with songs accessible to all with artistic captions gathered those who took part in consultations as well the experts who worked on the actual standard. European Federation of Hard of Hearing and International Federation of Hard of Hearing were involved in both.

As VIP's and experts involved joined in dance together, the message was clear:



WHO-ITU does not want us to stop listening to music. They want us to listen responsibly, so we can enjoy for longer.

During the celebrations, we had few speeches, one of them from Dr. Tedros Adhanom Ghebreyesus, WHO Director General said: "Given that we have the technological know-how to prevent hearing loss, it should not be the case that so many young people continue to

damage their hearing while listening to music. They must understand that once they lose their hearing, it won't come back. This new WHO-ITU standard will do much to better safeguard these young consumers as they go about doing something they enjoy."

The new global standard builds on European Union Directive on music players, see this article from Hear -it https://www.hear-it.org/New-EU-standards-for-personal-music-players-and-mobile-phones. Those who buy smartphones in EU are familiar with prompts with warning about prolonged listening to loud music over a time. This is because there is an automatic default in our devices which trigger those warnings.

ITU-WHO standard which was developed at ITU-T SG 16 question 28 aims to go further, the Safe listening devices and systems: a WHO-ITU standard recommends that personal audio devices include:

- "Sound allowance" function: software that tracks the level and duration of the user's exposure to sound as a percentage used of a reference exposure
- Personalized profile: an individualized listening profile, based on the user's listening practices, which informs the user of how safely (or not) he or she has been listening and gives cues for action based on this information.
- Volume limiting options: options to limit the volume, including automatic volume reduction and parental volume control.
- General information: information and guidance to users on safe listening practices, both through personal audio devices and for other leisure activities.

What about hard of hearing people you may ask? We can follow the guidance and use it in similar way. Our hearing aids and cochlear implants when fitted by audiologists or hearing aids professionals are set to max safe level of noise input.

What are the next steps? Civil society, in particular professional associations and others that promote hearing care including hard of hearing organisations also have a role to play in advocating for the standard and in raising public awareness about the importance of safe listening practices so that consumers demand products that protect them from hearing loss. Our role is to educate and explain what it means to live with hearing loss, after all preventions is always better than cure.

The WHO-ITU toolkit for implementation of the global standard for safe listening devices provides practical guidance on how to do this https://apps.who.int/iris/bitstream/handle/10665/280086/9789241515283-eng.pdf

While we are now entering implementation of this standard, we are already preparing next steps of tackling recreational noise exposure looking at concerts, bars and other public spaces so watch this space!

Lidia Best





TIN-ACT 2019 - an update: Dedicated to **understanding tinnitus**

TIN-ACT is a European consortium that investigates tinnitus ("ringing in the ears").

Tinnitus is a very common and potentially devastating condition. People with tinnitus continuously hear a penetrating phantom sound in absence of actual sound. An estimated 50.8 million EU citizens hear tinnitus, of which 5.1 million are severely bothered by it. Tinnitus can be enormously debilitating and leads to difficulty concentrating, lack of sleep, anxiety, and depression. Even mild forms of tinnitus reduce productivity due to difficulty hearing and concentrating at work and also resting and relaxing during leisure time. In order to cure tinnitus, we need to bridge the gap between basic fundamental research, applied clinical research and product development. Our aim is to understand the basic neural mechanisms of tinnitus, and to find ways to measure and treat tinnitus.

News

Forth TIN-ACT Workshop (Nottingham – Sep. 30 to Oct. 4, 2019)

The University of Nottingham held our recent TIN-ACT workshop in the first week of October. Meeting most of the TIN-ACT members, the researchers revealed new outcomes of their projects. Additionally, the invited scientists gave lectures in the fields of neuroimaging, audiology, hearing aids, and etc. As previous workshops, the Ph.D. students participated in training programs, this time about "Research and Ethics" and "Project and Time Management".

Furthermore, TIN-ACT members visited some of the labs at the UoN, particularly, the "Sir Peter Mansfield" Imaging Center, a prominent name in the history of Magnetic Resonance Imaging!

Third TIN-ACT Workshop (Berlin – May 07 to 11, 2019) Charite University Hospital hosted the recent TIN-ACT workshop in Berlin. In this scientific gathering,



the Ph.D. students started the event with a 2-day training concerning Scientific Communication and Outreach. On the following days, they presented the latest progress on their Ph.D. projects as posters. Also, several lectures were given by scientists from Charite University, University Hospital Jena, Eberhard Karls University Hospital Tuebingen, National Institute for Health Research Nottingham, and Otto von Guericke University Magdeburg.

As always, the host university planned an amazing social event for the TIN-ACT members, and this time, visiting the Einstein Summer House, in Caputh!

Second TIN-ACT Workshop (Erlangen – February 04 to 08, 2019)

The second TIN-ACT workshop was held up at University Hospital Erlangen on the first week of February. The early stage researchers participated in a 2-day training course concerning Ph.D. project management and presentation skills. Also, the latest progress in the Ph.D. projects was presented to the principal investigators.

More information: At the website: www.tinact.eu Our contact persons are: Volker Albert and/or Marcel

This project has received funding from the European Union's Horizon 2020





Figure 1: Presenters at Hearing Aid Developers Forum in Oldenburg June 2018, From left: Prof Inga Holube Jade Hochshule Oldenburg, Dr. Niels Pontoppidan, Eriksholm Research Centre, Oticon, Lidia Best, Vice President European Federation of Hard of Hearing, and Dr. Jeff Cruxley, Starkey Hearing Technologies

Niels Pontoppidan, EVOTION Project Coordinator and Lidia Best

BIG DATA

supporting public hearing health policies

EVOTION is a three-year Horizon 2020 Research and Innovation project funded by European Union with the objective to develop prototype platform that enables insights from and analysis of big data hearing health data. Other big data research projects on hearing health care has focused on either personalization or enhancing clinical practice. EVOTION further adds the dimension of big data supporting hearing health policies. The data collection is completed after 1000 hearing aid users used the EVOTION hearing aids for 12 months whilst also carrying

a phone that collected data about sound environment and hearing aid controls from the hearing aids as well as doubling as hearing aid remote control, auditory training platform, and hearing assessment platform. In addition to being fit according to the participants audiogram, the EVOTION hearing aids had 4 settings with different rules for activating noise reduction, one with low help (requires more noise to activate noise reduction with less attenuation of noise when activated), one with medium help (where noise reduction is activated at moderate noise levels and with



EVOTION Logo

moderate attenuation of noise, one with high help (requires only some amount of noise for activation of noise reduction at a strong level) and high+ (the high settings with additional attenuation of all sounds from rear and side). The hearing aid users could shift their hearing aids between those 4 settings as they wished with a remote-control app or the buttons on the hearing aids.

From the very beginning the EVOTION partners realized that for a platform to support policy making, then the platform should also include services that support personalization for the hearing aid user and services that support hearing care professionals in their rehabilitation tasks. To fulfil this ambition EVO-TION invited Lidia Best to for the EVOTION Advisory Board and Ethics Board to secure the voice of the users along with inviting Mark Laureyns from the European Association of Hearing aid Professionals to the EVOTION Advisory Board to represent that voice.

The mutual exchange of information has also continued outside of EVOTION, and June 2018 Lidia Best presented her views on data logging and big data analysis from the user perspective at the Hearing Instrument Developers Forum organized at University of Oldenburg along with my presentation of insights from the preliminary analysis of data from EVOTION hearing aids.

Key highlights from the EVOTION project

- 1) Most hearing aid users are fully capable of handling advanced hearing aids with multiple settings and the smartphone. However, ease of use remains important as it is an aid which is being used to support everyday life and thus any disturbances from connectivity issues should be avoided.
- 2) While respecting privacy and not being at all able to restore what was being said, the data about

EFHOH NEWSLETTER |



First EVOTION Advisory Board meeting September 2017. Prof. Andrew Smith (CITY University & London School of Hygiene and Tropical Medicine), Lidia Best (EFHOH), Christina Papanikolau (Director of ESY - Greek National Health System)

sound environments from the hearing aids reveals some very interesting aspects of everyday life with hearing aids.

- When looking at the sound environments across an average day, data shows that mornings are dominated by quiet (low sound level) situations followed by working hours where speech and speechin-noise dominates. Around 6 pm speech dominates, and late in the evening the quiet environment dominates again.
- 4) As the average day progresses, on average the use of high and high+ increases possibly as people become more fatigued and need more help. The shift to settings with more help is furthermore very pronounced in noisy situations around 6 pm.

Lidia Best, Member of EVOTION External Advisory Board

At the time I was asked to join the Advisory Experts Board, I was keenly following data logging used in hearing care, its handling as well as hearing and users and professional relationship.

From the outset, it become clear we have balancing act of user privacy, transparency and disclosure at the heart of data logging and this project. As we went on with the project, we looked at how national policy may be influenced by information gathered by researchers. Lastly, I wanted to find out more about user experiences using highly sophisticated hearing aids since majority of study participants were from UK.



In April, I was invited to take part in a workshop for EVOTION project participants taking place in London. Having spent time with participants and listening to question and answers session I realized their stories were all familiar to me and my colleagues and hearing their positive experiences with EVOTION hearing aids and audiologists' person-centered approach confirmed taking right advocacy efforts in this field. With EVOTION project, participants told me they felt valued as a person and a hearing aids user, their confidence and quality of life boosted and feeling part of family and society again. Some have had improved employment opportunities as the result of participating in this project. The dedication of professionals and users involved in this project cannot be underestimated.

The workshop showed that investing in quality of hearing aids, giving a choice with aid and programming thus improving quality of fitting in close partnership with the user makes economic sense and promises to banish dreadful notion of "hearings aids in the drawer".

The latest results from data are indeed very useful for another reason, it confirms the existence of "listening fatigue", something we the hearing technology users know and talk about but finally we have further evidence in confirmed user's behavior study. We can use all those findings further and hopefully influence different areas of policy that matter to those living with hearing loss.

Being part of the EVOTION External Advisory Board was great opportunity to make positive influence both with hearing care professionals, researchers in the EVOTION project and in Oldenburg to expand

on this shared knowledge with hearing instruments developers.

What we learned together!

The EVOTION project takes hearing research out in the real world and acts on data collected in the real world. Therefore, the role of real hearing aid users as participants and advisors has had great impact on the project at the daily and overall level. Once we got into the discussions, we realized that we where driven by the same ambition to conduct research and find the insights that will improve future hearing care for those who needs this. Based on this, we genuinely recommend others to bring users and researchers closer together and involve each other our projects. In the end, if we want to improve hearing health care in Europe, all stakeholders must contribute to this covering users, practitioners, industry, and researchers. Only if we stand united will we succeed in raising the awareness about hearing difficulties and the beneficial hearing solutions.

We hope to see more projects on hearing loss and hearing care receiving much needed funding from European Commission, such as ours receiving funds from Horizon2020.

Niels Pontoppidan and Lidia Best

International Hearing Access Committee













Telecoil and Hearing Loop Obsolescence 10-15 years and beyond

The International Hearing Access Committee (IHAC) aims to estimate the timeframe of the transition from existing telecoil audio transmission via hearing loops (HL) and other assistive listening systems (ALS) to a platform of digital audio streaming directly into hearing instruments.

Hearing instrument users require continued quality hearing access in public places which is currently provided by telecoils (TC) and HL/ALS. IHAC recognizes the European Hearing Instrument Manufacturers Association (EHIMA) has taken serious steps since 2014 to develop a standard hearing aid profile (HAP) for Bluetooth connectivity. This will ultimately permit direct streaming of high-quality stereo audio signals into hearing instruments. EHIMA admits this process is taking longer than expected.

Consumer organizations,² while excited about what the future will bring, are concerned that premature announcements will discourage research in TCs and lead to HL/ALS neglect and abandonment before such a new technology is fully matured and carefully evaluated by end users.

While an accurate estimate of the timeframe of a worldwide transition from analog to a digital audio streaming system cannot currently be made, it is reasonable to believe that TC, HL/ALS usage will continue for the next 10-15 years and beyond.

The rights of users to communication access must be continued and maintained during this period of technological change. End users should not be compromised by the promise or an overly optimistic timeframe for adoption and expectations of a future technology development.

Communication access via telecoils

Telecoils are designed to improve communication access for people with hearing loss³ in venues where distance, reverberation and background noise prevent comprehension.

Telecoil Advantages for hearing instrument aid users

- ease of use by people of all ages
- availability in nearly all hearing devices
- affordability, no cost to users beyond the price of the hearing aid
- energy efficiency, little or no battery drain
- universality, any TC can connect to any ALS. No matter their brand of HA or brand of ALS
- very low latency, which is important in real-time events.

Telecoil Disadvantages

- have only 1 channel, no stereo
- are sensitive to electromagnetic interferences.

June 2019

 $^{^1\,}https://hearinghealthmatters.org/hearingnewswatch/2014/hearing-industry-seeks-new-wireless-standard-hearing-aids-\ t-coil-advocates-say-fast/$

² International Federation of Hard of Hearing People, Hearing Loss Association of America and European Federation of Hard of Hearing

 $^{^3\} www. access-board.gov/research/completed-research/large-area-assistive-listening-systems/1-introduction$

International Hearing Access Committee













Membership

Andrew Thomas, chair, International Hearing Loop Manufacturers Association (IHLMA)

Aïda Regel Poulsen, general secretary, European Federation of Hard of Hearing People (EFHOH)

Dr. Ruth Warick, president, International Federation of Hard of Hearing People (IFHOH)

Avi Blau, vice-president, International Federation of Hard of Hearing People

Dr. Hans Seidler, German Hearing Loss Association (DSB)

Dr. Juliëtte Sterkens, Hearing Loop Advocate, Hearing Loss Association of America (HLAA)

Dr. Rob Drullman, secretary, European Hearing Instrument Manufacturers Association (EHIMA) Technical Committee

History

Formation of the International Hearing Access Committee (IHAC) was proposed at the 4th International Accessibility Conference on Hearing Loops, Berlin, Germany, October 6-8, 2017. The Committee was established in 2018 and has held three online meetings

Purpose

- 1. foster understanding and increase awareness of the benefits of sound and assistive listening systems for persons with hearing loss with particular attention paid to hearing loop technology
- 2. further development and continued improvement in hearing instruments and the availability of hearing loop technology
- 3. foster improved telecoil function and innovation
- 4. raise awareness of the benefits of telecoils among the providers in the hearing industry.

Objectives

- develop a worldwide strategic plan for the development and promotion of hearing technology including hearing loop technology
- 2. develop a mapping plan of existing technology and resources
- 3. assist IFHOH in the planning for the next Future Loops and Technology event/conference.

Scope

The scope of the work is recognized to encompass a wide audience:

- 1. consumers and advocates
- 2. audiologists, hearing aid and cochlear implant industry providers
- 3. architects, sound engineers, audio/visual designers and installers
- 4. facilities covered by disability laws and accessibility committees
- 5. manufacturers of assistive listening systems and others interested in this technology.

biha Press Release (Bundesinnung der Hörakustiker KdöR) in Germany

Intelligent Loud-Speaker in the Ear Inclusion for Hard of Hearing People

Mainz (Germany), May 16th,2019. Although the Convention on the Rights of People with Disabilities of the United Nations has been in effect since 2008, people with disabilities still struggle with barriers in their daily lives. The commissioner for people with disabilities of the German Government recently demanded further efforts in the realm of inclusion to further improve the situation for people with disabilities. Inclusion is also important for people with hearing loss.

Going to a cinema or a theater, attending music events or listening to a lecture – for people with hearing loss these are very often real challenges. A babble of voices and large spaces interfere with hearing intelligibility. Frequently, in addition to the desired sounds and words, there is disturbing background noise because acoustics in public areas are not always suited to people with hearing problems. They hear only fragmentarily or with big effort. The person who does not understand everything quickly feels excluded und loses the joy of listening or participating in the conversation. A possible consequence is social isolation instead of participation in public life. Audio Frequency Induction Loop Systems, also called hearing loops, help people with hearing systems and support inclusion. Audiologists / Hearing Systems Acousticians can counsel and help.

Thanks to the latest technology, modern hearing systems wirelessly connect with digital sound sources, such as smart phones, sound systems, and television sets, via Bluetooth. This enables hearing without disturbing background noise. Bluetooth, however, has a big disadvantage: its range is limited to a few meters / yards.

The Audio Frequency Induction Loop System / "Hearing Loop" is a useful system for Hard of Hearing People, which is suitable for public spaces. Hearing aids with a telecoil (and cochlear implants) can directly couple to these systems, thus enabling the users to detect acoustic signals with distortion-free reception. Music, theater performances or lectures are transmitted directly into the ear regardless of distance or room acoustics. The hearing system turns into an intelligent loudspeaker in the ear, with selective filtration.

Many public agencies have already made access to their venues "barrier-free," and their premises are equipped with an Audio Induction Loop System / Hearing Loop. Where an induction loop wire is installed in the floor or on the wall, people with hearing systems can receive audio signals in the same quality and volume via their hearing systems. With a sign at the entrance in the form of a blue or yellow square with a stylized ear and the letter "T" these "barrier-free" rooms are easy to recognize. If there are only limited areas equipped with an induction loop, such as in a cinema, concert hall or church, then these areas are marked appropriately.

A telecoil integrated in the hearing system can be activated by the person using the system by using a pre-programmed setting. "When requested, the audiologist / hearing aid acoustician can check this free of charge; it takes only a few minutes," says Marianne Frickel, Hearing Acoustician Master Craftsperson and President of the German Federal Guild of Hearing Acousticians (biha). Hearing acousticians are available as expert contact persons and can give a helping hand by setting up the systems. There are no external receivers necessary — all is included in the hearing system.

Additional information about hearing and many useful facts can be found at www.richtig-gut-hoeren.de (translated by Siegfried Karg)

DON'T LET HEARING LOSS LIMIT YOU



Hearing for life

World Hearing Day, 3 March 2020





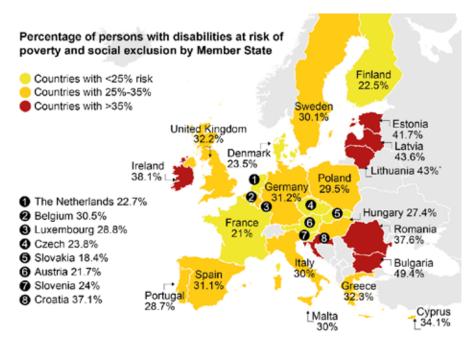


We demand strong action to reduce poverty of persons with disabilities in EU

Luminita, from Romania, was denied education and, when working, had her wages withheld. Sven, from Sweden, lives in fear of losing his assistance and having to live in a residential institution. Maria Chiara's family, in Italy, and Joncour's family, in France, live in a precarious condition because the state does not pay for their personal assistance. Matthieu was expelled from the UK to his native France because he was perceived as a "undue burden".

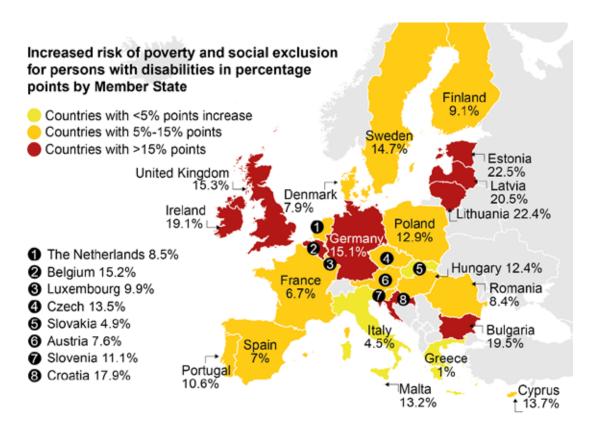
These examples show how EU countries have largely failed at reducing poverty of persons with disabilities: 28.7% of the persons with disabilities living in the EU, more than 1 in 4, are poor or at risk of poverty.

The situation has actually gotten worse since 2010 in 11 countries: Estonia, Luxembourg, Germany, Sweden, Ireland, Czechia, Lithuania, Italy, Netherlands, Malta and Spain.



Source: <u>European union statistics on income and living conditions</u> 2018, except Slovakia, Ireland and the UK for which that data is from 2017

In all EU countries, persons with disabilities are more likely to be poor and more likely to be unemployed than persons without disabilities. Not only are persons with disabilities poorer, but they also face extra costs from living in a society that is not adapted to them: costs estimated at 23,012 euros/year in Sweden or 14,550 euros/year in Belgium, for example.



Source: <u>European union statistics on income and living conditions</u> 2018, except Slovakia, Ireland and the UK for which that data is from 2017

The situation is even worse if they live in rural areas, are woman, young, belong to ethnic minorities and/or other discriminated groups.

These are just some of the many findings from our upcoming European Human Rights report. Overall, our report shows that EU countries have failed in ensuring proper protection and support of persons with disabilities, especially in the wake of the financial crisis.

This is why today, on the International Day of Persons with Disabilities, we call on the European Union and national and local authorities for stronger measures to fight the poverty of persons with disabilities, including:

 Fixing disability assessment: all EU countries should follow an approach that looks at a combination of impairment, functional, social and environmental considerations. The recognition of disability should be harmonised and recognised throughout the EU, so persons with disabilities don't have to submit to assessments each time they move countries.

- Stopping the "benefits trap": Do not try to push persons with
 disability into employment by reducing disability allowance. Ensure
 disability benefits provide a stable, liveable income. Ensure benefits
 account for the extra costs persons with disabilities incur. Ensure
 benefits are not cut nor stopped when a person with disabilities starts
 work.
- Investing in accessibility, support structures and services: Ensure
 housing-first solutions that allow people with disabilities to live in the
 community. Invest EU and national funds in the accessibility of
 mainstream services to minimise disability-related costs. Invest in
 support services including housing and living support systems, health
 and mental health support systems and support to employment.

We call on the EU and its Member States to honour their commitments to the UN Convention on the Rights of Persons with Disabilities and to ensure that all persons with disabilities are able to live with dignity in the community, with equal access and equal rights.



THE EU OMBUDSMAN

The EU Ombudsman is very important to us and to the protection of the rights of persons with disabilities in the European Union. The treaty on the Functioning of the EU- article 228, describes the institution of the EU Ombudsman and you can find every detail of the Ombudsman's work on the website - which has been made accessible in recent years.

The website describes in detail what the Ombudsman can do, and how a person can make a complaint:

"The European Ombudsman investigates complaints from individuals, businesses and organisations about maladministration by the institutions, bodies and agencies of the European Union. Maladministration occurs if an institution or body fails to act in accordance with the law or the principles of good administration, or violates human rights.

Maladministration can include administrative irregularities, unfairness, discrimination or the abuse of power, for example in the managing of EU funds, procurement or recruitment policies. It also includes the failure to reply, or the refusal or unnecessary delay in granting access to information in the public interest. Complainants do not have to have been affected by the issue(s) complained about."

The current Ombudsman is Emily O'Reilly. In December, the European Parliament will elect an Ombudsman for the next 5 years. During her present term, the Ombudsman has done a lot of work to promote and especially to monitor the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD).

Indeed, the European Ombudsman plays an essential role in monitoring the implementation of the CRPD at the EU level, both as a member of the EU Independent CRPD Monitoring Framework, but also in their role to investigate complaints, and launch own initiative inquiries into important issues related to the accessibility and inclusiveness of the EU institutions.

During her present term the Ombudsman has:

 Looked into how the European Commission ensures that its websites and the online tools are accessible for persons with disabilities. The Ombudsman opened an inquiry and asked the Commission about its use of accessible formats (like



'easy-to-read'), how it enables users to provide feedback on accessibility, and what training it provides for staff members on accessibility issues. The Ombudsman closed her inquiry in January 2019 with six suggestions for improvement.

- Looked into how the European Commission ensures that the fundamental rights enshrined in the EU Charter of Fundamental Rights are complied with when EU cohesion policy and its structural funds are implemented by Member States. The Ombudsman defined guidelines for the Commission on how to improve.
- that the European Anti-Fraud Office (OLAF) failed to make the fraud notification form on its website accessible for persons with a visual impairment.
- inquired into two complaints from visually impaired candidates who participated in selection procedures for recruiting EU civil servants, which were organised by the European Personnel Selection Office (EPSO). The Ombudsman welcomed that EPSO, in response to her recommendations, updated the information provided to candidates on measures for accommodating their special needs. She also welcomed EPSO's proposal to enable visually impaired candidates to sit computer-based tests off-site, using remote access technologies. However, the Ombudsman was not fully satisfied with the timeline proposed by EPSO for making its online application form fully accessible and noted this again to EPSO in her decision closing the inquiry.
- Chaired the EU Independent CRPD Monitoring Framework and taken part in all activities of the EU framework.

We are part of the EU Independent CRPD Monitoring Framework, together with the Ombudsman's office - therefore we meet regularly. In addition, the Ombudsman's office reaches out to us to discuss specific complaints and enquiries. The Ombudsman herself took part in the 4th European Parliament of Persons with Disabilities.

Candidates for the role of Ombudsman for the next 5 years are:

- Giuseppe Fortunato
- Julia Laffranque
- Nils Muižnieks
- Emily O'Reilly
- Cecilia Wikström

2020 CALENDAR

January

 23 - 24 January, Brussels (Belgium): EDF Executive Committee meeting

February/March

- 28 February, Brussels (Belgium): EDF Executive meeting
- 29 February 1 March, Brussels (Belgium): EDF Board and Associate Meeting

May

- 8 May, Zagreb (Croatia): EDF Executive Committee Meeting
- 9 10 May, Zagreb (Croatia): EDF Annual General Assembly

June

- 18 22 June, Madrid (Spain): World Blind Summit October
 - 30 October, Berlin (Germany): EDF Executi Committee meeting
 - 31 October -1 November, Berlin (Germany): EDF Board and Associate meetings

December

1 - 2 December, Brussels (Belgium): European Day of Persons with Disabilities (EDPD)

HOW TO EASILY CONTACT MEMBERS OF THE EUROPEAN PARLIAMENT

In order to find the contact details of Members of the European Parliament (MEPs) you can use the search

tool of the European Parliament website. Each MEP has a webpage in which you can find her/his email, phone numbers and social media channels. If you want to write to her/his assistants you just need to see their names and compose the email address as follows firstname.familyname@europarl.europa.eu.

However, there is even an easier way to get emails of MEPs, all at once, by using a freely available mobile application called "EP Mobile" (available for Android, and for iOS). This app is developed and updated by a public affairs consultancy, and it allows to create mailing lists by countries, Committees of the Parliament, political groups and even by legislative dossiers.

FINNISH PRIME MINISTER ANTTI RINNE MEETS WITH EUROPEAN DISABILITY MOVEMENT'S DELEGATION

Delegation of the European Disability Forum and of the Finnish Disability Forum meets with Finnish Prime Minister Antti Rinne

On Friday, the 8 November, representatives of the European Disability Forum and of the Finnish Disability Forum met with Finnish Prime Minister Antti Rinne. Finland currently holds the Presidency of the European Union.

We stressed the importance to achieve equal rights for persons with disabilities, 100 million persons with disabilities in the EU, and briefed the Prime Minister on the priorities of the disability movement, including:

- Achieving full implementation of the UN Convention on the Rights of Persons with Disabilities and in particular ensuring that the Council itself established s focal point for the CRPD
- Ensuring a strong European Disability Rights Agenda post 2020.
- The importance of Finland as a leader of disability inclusive development, humanitarian action and international cooperation and the potential for promoting a strong disability inclusive international cooperation approach at EU level
- The importance of an ambitious application of accessibility laws, including transposition of the European Accessibility Act and implementation of the Web Accessibility Directive.

 The importance of implementation of the EU Pillar of Social Rights and removing all barriers to employment for persons with disabilities, including through the use of EU funds- the next EU budget should be used to invest in an inclusive accessible Europe

VICE-PRESIDENT DESIGNATE SCHINAS MEETS WITH EUROPEAN DISABILITY FORUM

On Tuesday, the 29 October, representatives of the European Disability Forum, led by our President Yannis Vardakastanis met with Vice-President designate for Protecting the European Way of Life, Margaritis Schinas.

The EDF delegation stressed the importance to achieve equal rights for persons with disabilities, 15% of the population, and briefed the Vice-President designate on the priorities of the disability movement, including:

- Ensuring that the Commission's focal point on the UN Convention on the Rights of Persons with Disabilities has the necessary resources and a central position in the Commission's services dedicated to fundamental rights.
- Adopting an ambitious and well-resourced European Disability Rights Agenda 2020-2030, that
 makes the UN Convention on the Rights of Persons with Disabilities a reality in Europe and the
 world.
- Ensuring a human rights approach to refugees and migrants, including proper protection and support of refugees and migrants with disabilities.
- Adopting equal treatment legislation that will protect persons with disabilities from discrimination in all areas of life, including multiple and intersectional forms of discrimination.
- Gender equality policies and the fight to eliminate violence against women and girls should include women with disabilities.

EUROPEAN SURVEY ON DISCRIMINATION: EUROBAROMETER WITH OVER 25.000 RESPONDENTS

Today the European Commission released an Eurobarometer on discrimination. This Eurobarometer is

an in-depth study that surveys over 25.000 people on attitudes and perceptions on discrimination.

Regarding disability, the main findings are:

- Almost half of respondents think discrimination on the basis of disability is widespread in the country;
- Respondents are increasingly comfortable with he idea of a person with disabilities holding the highest political office;
- 84% of respondents would feel comfortable having a colleague with disabilities;
- More than two thirds of respondents would feel comfortable if their child was in a love relationship with a person with disabilities.

HEARING ON THE FUTURE EU DISABIL-ITY RIGHTS AGENDA: WHAT WAS DIS-CUSSED?

On Monday 21 October, EDF President, and member of the Economic and Social Committee (EESC), Ioannis Vardakastanis, presented the draft EESC opinion on the follow-up to the EU Disability Strategy 2010-2020. The EESC's and EDF's proposed name for the future strategy is the 'EU Disability Rights Agenda 2020-2030'.

The EESC Opinion sets out clear demands and suggestions for how the Disability Rights Agenda should look, what it should aim to do, and what specific actions should be taken to achieve this. Comments from the floor focused on access to employment, quality inclusive education that also takes into account support for teachers, stronger consideration of families and carers, and taking a much stricter approach to transition from institutional to community-based care, to name but a few.

EU LEADERS: PERSONS WITH REDUCED MOBILITY NEED EQUAL RIGHTS TO TRAIN TRAVEL!

Over 200 politicians and organisations call on the Council to improve the Rail Passenger's Rights regulation.

When Horst tried to take an early morning train to a meeting with the German ministry of Health, he was denied boarding: the train was there, but assistance was still closed. Taking a train after a flight is also an

impossible task: most train station require pre-notification of 48 hours, which leaves passengers with reduced mobility stranded if the flight is late.

This is why 10 Members of the European Parliament and over 200 organisations active in the fields of disability, rights of older people, environment and passenger rights published a joint letter to EU leaders calling on them to scrap pre-notification periods for assistance during train travel in the upcoming revision Rail Passenger Rights' Regulation.

Train travel is increasingly on focus as a more environmentally sustainable mean of transport. However, the sad truth is that millions of persons with reduced mobility cannot access it freely, as assistance to board the train is restricted and subject to lengthy pre-notification periods.

The revision of the Rail Passenger's Rights regulation has the potential to take a step in the right direction, by making assistance available at all times. However, some EU Member States are sadly blocking this improvement. The letter calls on them to, instead, support the proposal of the European Parliament.

Yannis Vardakastanis, President of the European Disability Forum stated: "The future should be sustainable. The future should be inclusive. We call on EU leaders not to stand in the way of the future. Persons with disabilities should not have to jump through hoops to access train travel, and therefore they should take away the pre-notification barrier."

HONORING ERASMUS FATHER DOMENI-CO LENARDUZZI

It is with great sorrow that we learned of the death of Domenico Lenarduzzi, ex-Director General for Education at the European Commission and considered by many to be the "father" of the ERASMUS programme. As a person with disabilities himself, Domenico paid special attention to the mobility of students with disabilities

THE EU CHARTER OF FUNDAMENTAL RIGHTS

In 2000, the European Union (EU) adopted a "EU Charter of Fundamental Rights", a legal document which combines all the personal, civic, political, economic and social rights of people within the EU into a single text. Previously, these fundamental rights were

mentioned in different texts making them difficult to identify.

The Charter is divided into six titles:

- Dignity
- Freedoms
- Equality
- Solidarity
- Citizens' rights
- Justice

The rights to life, to integrity, to marry, to education and to work, are recognised among many others. The Charter has also included fundamental rights that reflect modern society, such as data protection, guarantees on bioethics and transparent administration.

What about the rights of persons with disabilities? All the rights in the charter apply to persons with disabilities without discrimination.

Article 21 of the charter specifically prohibits any discrimination on the ground of disability. Article 26 on integration of persons with disabilities says that the European Union "recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community." This includes reasonable accommodations and measures to promote accessibility and universal design.

The EU as an institution is forbidden to discriminate against persons with disabilities, and must respect all their rights, including in the laws it adopts. When an EU country implements a law adopted by the EU, for instance on passengers' rights, it is forbidden to discriminate on the grounds of disability. However, the charter does not apply at national level in areas where the EU has not adopted laws. For example, pupils with disabilities cannot use the charter to claim a right to inclusive education in their country, nor that they were discriminated against in (not) accessing education, because there is no EU law covering this area.

Read more on the Charter of Fundamental Rights on the website of the European Commission.

More questions? Contact Marine Uldry at marine. uldry@edf-feph.org.

EFHOH MEETINGS in 2020 & 2021

2020	2020	2020	2020
8 January	London	Evotion meeting	Lidia
7-8 February	Budapest	IFHOH board meeting	Marcel
4 March	Brussels	European Parliament Lunch Debate with AEA & EHIMA	EFHOH board
29 Feb -1 March	Brussels	EDF board meeting	Marcel
25 March	Barcelona	European Platform of Deafness, Hard of Hearing and Deafblindness	Aïda and Marcel
22-24 April	Copenhagen	TIN ACT meeting by Widex	Marcel and Volker
9-10 May	Zagreb	EDF AGA	Aïda and Marcel
17-21 May	Geneva	WHO and WHF meetings	Lidia
27-29 May	Budapest	IFHOH World Congress + EFHOH AGM	All board members
13-17	Barcelona	Live Text Access (LTA) project meeting	Aïda and Marcel
4-6 June	Lake Como/ Italy	HeAI 2020	One of the board members
September	Mechelen	TIN ACT meeting by Cochlaer	Marcel and Volker
9-11 October	Berlin	EDF board meeting	Marcel
1-2 December	Brussels	European Days of Persons with Disabilities	One of the board members
December	Copenhagen	TIN ACT meeting by Interaccoustics	Marcel and Volker
2021	2021	2021	2021
27-29 January	Barcelona	Media for All conference	Aïda and Marcel
June	Groningen	TIN ACT end conference	Marcel and Volker

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IFHOH 2020 World Congress in Hungary





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.