

European Federation of Hard of Hearing People

State of Hard of Hearing
people's rights in the EU

2016 Report

Legal Framework and the of Hard of Hearing People in the EU



The Prague Declaration and UN CRPD

Dear Reader,

Articles 11 and 14 of the EU Charter of Fundamental Rights confirm access to information and education as basic human rights. The EU has also adopted the UN Convention on the Rights of Persons with Disabilities (UNCRPD). The Convention states that its purpose is to *promote, protect and ensure the enjoyment of all human rights* by persons with disabilities.

For people who are hard of hearing this means ensuring they are made aware of services and their accessibility rights, particularly ensuring that their complex communication needs (such as lip reading or speech to text support) are understood and met by their country. This also means promoting, protecting and ensuring they have access to the same information and entertainment as those who do not have a hearing loss.

On April 6th 2013 our delegates at the EFHOH AGM in Prague signed the ‘Prague Declaration’ to improve *“the access of people with hearing disabilities to information”*. The Declaration itself asked the European Union to improve the quality of life of hard of hearing individuals by allowing citizens full access to information via their communication needs:

“Article 9 of the UN CRPD points out that the convention state parties should take necessary measures to secure that persons with a disability have equal access to information and well-functioning communication, including information and communication technology (IT) and systems.”

The Declaration sought to tackle inequality in the workplace and to ensure that people who are hard of hearing have fair working conditions, quality health care and the same meaningful social conditions that hearing people have access to. The Declaration also aimed to end the discrimination of hard of hearing people in society.

There is an estimated 15% of the world’s population that have a hearing loss, and under the United Nations Convention on the Rights of Persons with Disabilities (CRPD) hard of hearing people should be subject to the same living rights as others. At the European Federation of Hard of Hearing people, we feared that the legal requirements for hard of hearing people were not being met so we commissioned a survey to address whether our members felt like their rights were understood and to identify the gaps in the legal frameworks in countries within the EU. With this report we have written up our findings from the survey including

whether hard of hearing people are actually included in the design of services and the implementation of legislation for the communication needs for example.

This report will provide much needed empirical data on the considerable variability of the legal systems between EU member states. There are stories of success. However, our research shows that many member states still have a great deal of progress to make, such as a greater awareness of hard of hearing people as disabled people, if they are to meet the standards and terms of the UNCRPD and the Prague Declaration that are rightly demanded by the many millions of hard of hearing Europeans that continue to be denied their fundamental rights.

Those Europeans that have a hearing loss must have *access to the same goods and services* as everyone else if the EU is to claim that it promotes, protects and ensures the enjoyment of all human rights by persons with disabilities. Article 30 of UNCRPD recognises the right of persons with disabilities to have *equal access to participation in cultural life, recreation, leisure and sport*.

Unfortunately the stories of success and progress are matched by areas of concern and the enduring frustration of the many millions of Europeans who continue to be unjustly excluded from society and the legal systems that seek to protect them. For example, 72.22% of those surveyed said that they felt their rights were only partially met by their country. Furthermore, in Norway, although they felt their rights were recognised by law in reality this was not practised. Additionally, in terms of employment support more needs to be done to promote hard of hearing people's varied communication methods and support needs such as note taking and speech to text systems. Together with this, more also needs to be done to make hard of hearing people aware of all of these systems as some members didn't know these services existed.

EFHOH is keen to work together with organisations across the EU in order to guarantee fundamental human rights and an involvement in the legislation that seeks to protect disabled and hard of hearing people.

Sophie Kleanthous | Policy Officer | European Federation of Hard of Hearing People



Who are we?

EFHOH - European Federation of Hard of Hearing People

The European Federation of Hard of Hearing People exists to represent hard of hearing people at a European level in dialogue with the European Union, the Members of the European Parliament, and other European authorities.

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

<http://www.efhoh.org/>

What does "hard of hearing" mean?

Hard of hearing and deafness is a problem which affects 51 million Europeans.

The term is used as a definition covering everybody with a hearing loss, ranging from light hearing loss to adult, profoundly deafened users. Unlike pre-lingual deaf people, hard of hearing people develop and use the spoken language (with or without supportive signs).

Hard of hearing and late deafened people are reliant on visual text to ensure access to information on an equal basis with hearing people.

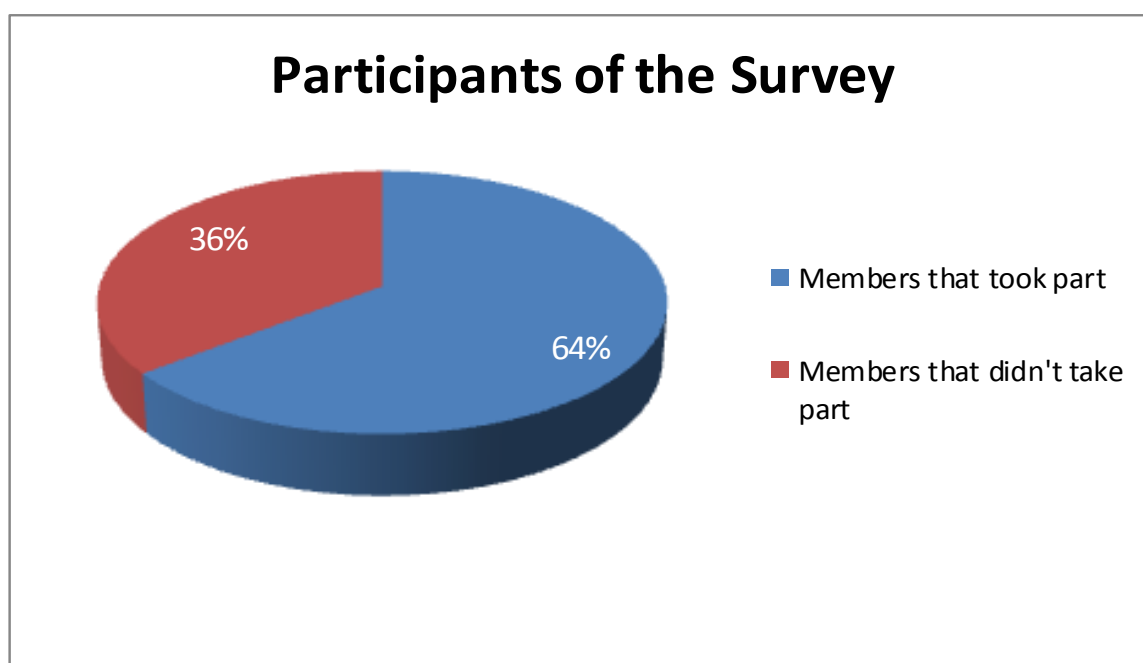


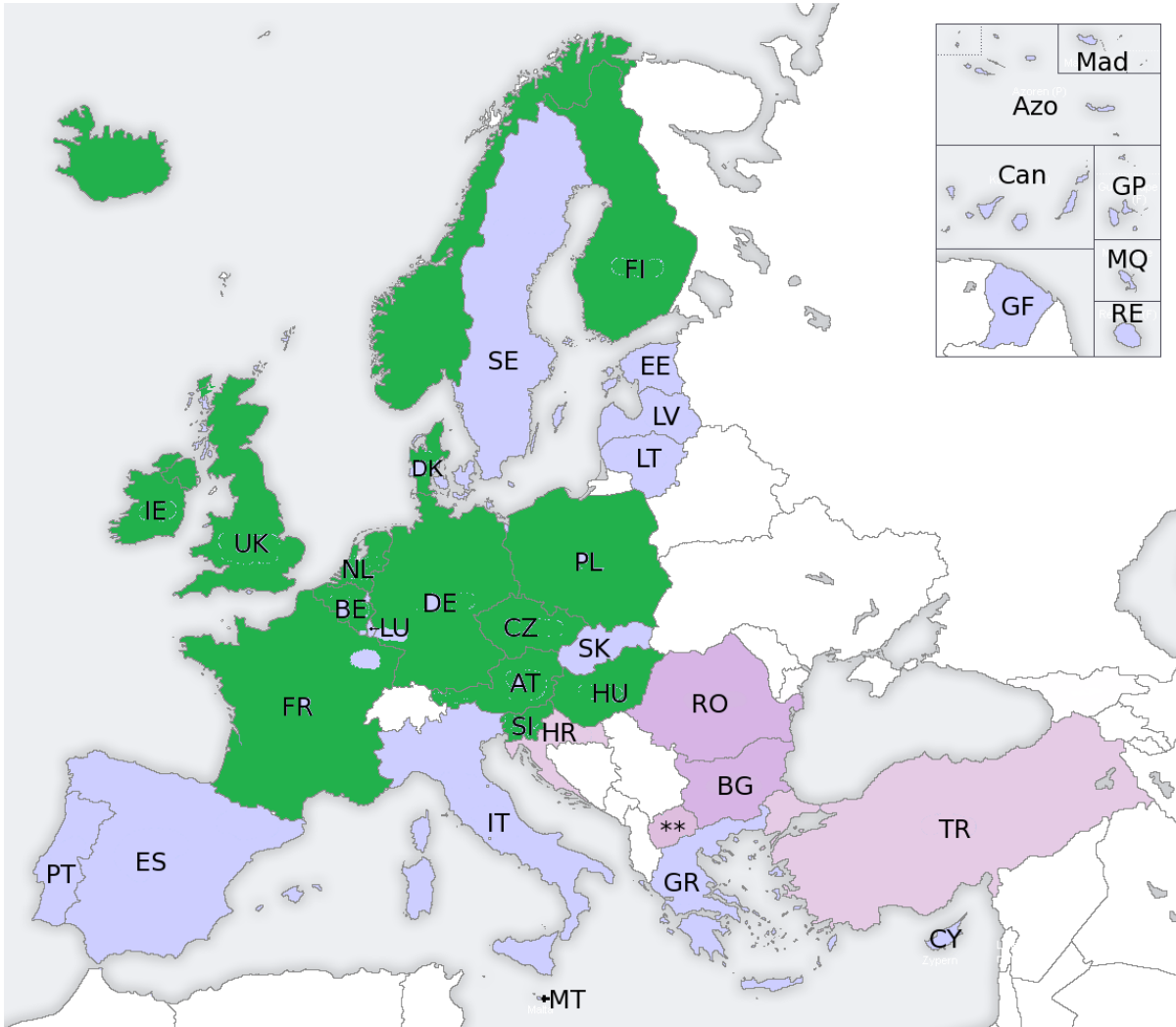
The EFHOH Legal Survey 2016

Background

EFHOH recently conducted a survey on the legal frameworks (the rights) of different European countries in relation to Hard of Hearing people. We had a total of 18 respondents to the survey, which is 64% of our total membership so a very high amount of interest, and a positive result for us. 18 members from 15 European countries took part. From the results analysed below it is very clear that more needs to be done to raise the profile of hard of hearing individuals in a legal protection context, and to ensure all hard of hearing from tinnitus to deafened people are recognised correctly as having a disability. So there is still a lot more work that needs to be done.

One trend that the data showed is that all the countries that took part in the study felt that further recognition was needed for those with hearing loss in all areas of society. Below is a graph to illustrate the percentage of our members that took part. Included is also a map of Europe which we have used to highlight which countries took part in relation to our overall membership.





Key:

= Member States who took part in the survey

+ = EU Member States

General Trends

The overall trends from this the ‘legal survey’ are overall worrying and shows that European countries are not doing enough to ensure hard of hearing people’s rights are met. Most countries for which we have data have shown that information on each legal system is available to the public but often not implemented effectively. Throughout this report, it will be demonstrated that some countries are leading the way in legal provisions for hard of hearing people, whilst others have a long way to go to ensure their needs are full accounted for and understood.

As with our ‘2015 State of Subtitling report’ a continued worrying general trend is that it is clear that much more needs to be done in terms of data collection. As can be seen in the analysis later in the paper, there are significant gaps in our members and European hard of hearing people’s knowledge about the political system in their country. For example, Austria answered ‘I do not know’ twice in the survey in regard to the different support systems one has a right to ask for from the Austrian government and if the law is clear on what is ‘reasonable adjustment’ for hard of hearing people. This makes the data incomplete. Nonetheless, from the data we can see a slight balance in both good and bad practise, some relative success stories but overall further clarification is needed in all European countries.

The Results

Different Types of Hearing Loss: Representation

Question two asked member organisations to list in full the Hearing loss groups that they represent. The majority of members, 22.22% said they represented Hard of Hearing People only, with a further 22.22% saying they represented deaf, hard of hearing and deafened people. Almost all respondents put ‘Other’ with 36% choosing this option, and three members choosing all of the options available. A list of the full responses can be seen in the table below.

Qu. 2 Table 1: The Different Hearing Loss Groups represented by our members

Organisation	Country	Hearing Loss groups they represent
Kuuloliitto Finnish HOH org	Finland	Tinnitus, Meniere Acoustic Neuroma, NF2, CI, ABI, HOH, Deafened
Høreforeningen	Denmark	Hard of hearing people, deafened, CI-users, Tinnitus and Meniere. HOH-children.
HOB	Belgium	Hard of hearing people
National Association of Deafened People United Kingdom (NADP)	The United Kingdom	Deafened People
Hungarian Association of Deaf and Hard of Hearing People	Hungary	Deaf, Hard of hearing and deafened people
Heyrnarhjalp	Iceland	Hard of hearing people

Kuuloliitto	Finland	Hard of hearing people, CI users Tinnitus/Meniere's sufferers, all except deaf (who only communicate with sign language)
Hearing Loss Association of America, Sprachrohr Austria	Austria	Meniere's sufferers
Deutsche Tinnitus-Liga e.V., Germany	Germany	Tinnitus Sufferers
Polska Fundacja Osób Słabosłyszących	Poland	HOH, late deafened, CI users, tinnitus sufferers
Zveza društev gluhih in naglušnih Slovenija	Slovenia	Deaf, hard of hearing, deafened people and cochlear implant user
The Norwegian Association for the Hard of Hearing - Norway	Norway	Hard of hearing people, deafened people, CI users, tinnitus sufferers, hard of hearing children and Meniere's sufferers
Hearing Loss Ireland	Ireland	Hard of Hearing People
Deutscher Schwerhörigenbund e.V., Germany	Germany	Deaf, hard of hearing and deafened people
Czech Union of the Deaf	Czech Republic	Deaf, hard of hearing and deafened people
NVVS/Hoormij	The Netherlands	Hard of hearing people
ARDDS	France	Deaf, hard of hearing and deafened people
Deutsche Tinnitus-Liga e.V., Germany	Germany	Tinnitus Sufferers

Question three, asked our members if they felt that the rights of Hard of Hearing people had been made an obligation in their country. We were unsurprised by these results with 72.22% saying that they felt that this was only partially the case, and only the United Kingdom said that they believed that their rights were completely and fully made an obligation in their country. In contrast Austria said that they felt that their rights were made an obligation but only to a limited extent.

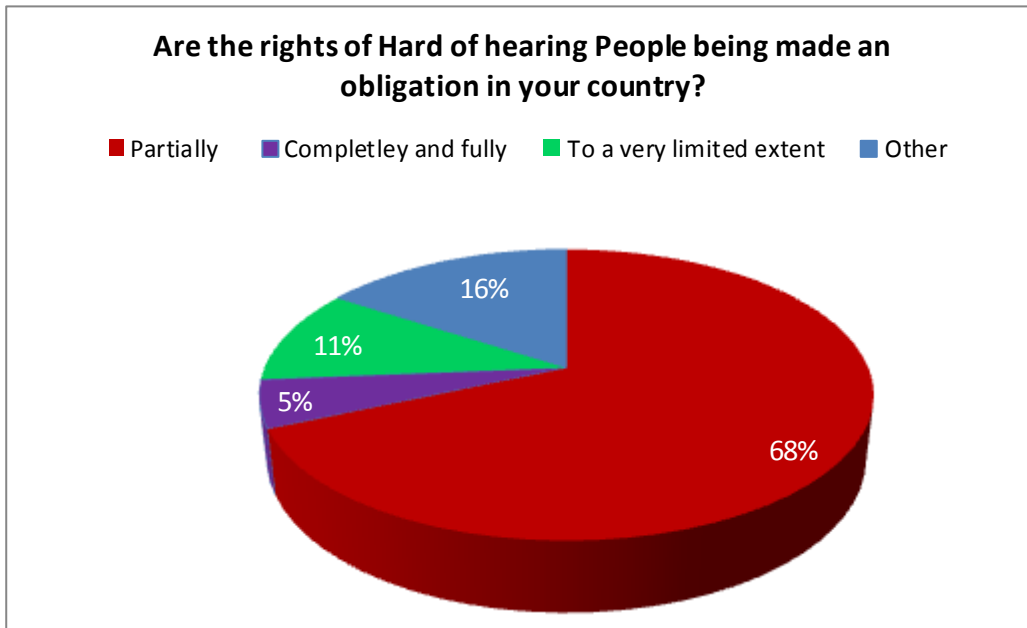
Furthermore, 3 members (16.67%) opted for 'other' and expanded their answers.

The Polish group, 'Polska Fundacja Osób Słabosłyszących' wrote that they felt the law was too vague, only viewing disabled people in a general way, which caused problems for specific legislation to be changed. They also noted that HoH people often do not have a certificate documenting their disability, and as a result the law cannot be accurately used to represent HoH (see graph and table 2 below).

In contrast, 'The Norwegian Association for the Hard of Hearing' noted that although by law their rights are recognised, in reality they are often not fully fulfilled. This is an increasing problem for the rights of hard of hearing people, so member states must focus on transparency and the recognition of hard of hearing people as disabled. Finally, the 'Czech Union of the Deaf' noted that it is very difficult to determine a hard of hearing person through state law, as hard of hearing people are only recognised as those who need a specific type of hearing equipment, which is problematic when HOH people's needs are far more complex than this, and so needs to be recognised in this way.

Qu. 3 Table 2: Are the Rights of Hard of Hearing People an obligation?

Do you feel that rights of hard of hearing people been made an obligation in your country?	Country
Completely and fully	The United Kingdom
Partially	Finland, Denmark, Belgium, Hungary, Iceland, Austria, Germany, Slovenia, Ireland, The Netherlands, France
To a very limited extent	Austria
No	0
Other	Czech Republic, Norway and Poland*



Qu. 2 Graph 2

The Different Needs of Hard of Hearing

Question four, asked respondents if they felt like their different needs were understood by their country and government. Although, again the answers we received were in line with what EFHOH were expecting, only 5% of respondents answered yes to this question with 66.67% respondents noting that they felt their needs were only partially understood and 22.2% answering ‘no’, that they didn’t think their needs were understood at all. A full country breakdown can be seen below in table 3.

The Czech Union of the deaf voted ‘other’ and argued that hearing people were consistently grouping hard of hearing people incorrectly and assumed that all of them used sign language. They elaborated this, saying:

“Some Hard of hearing people need sign language interpreting, come deaf speech to text reporting. Hearing people think that all people with hearing problem need sign language.”

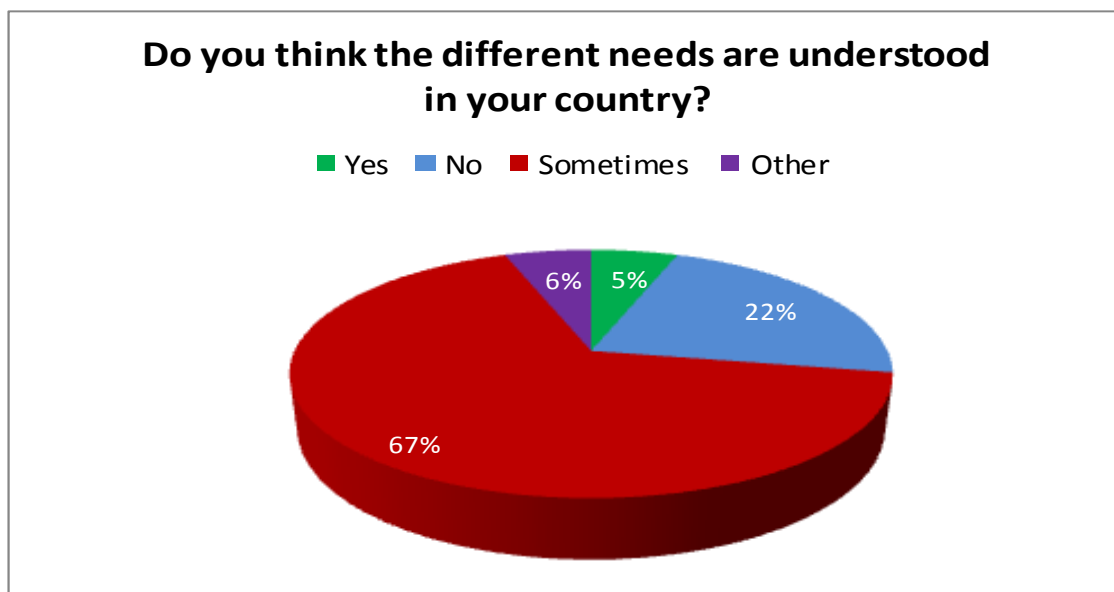
EFHOH understands therefore that Hard of Hearing members are not being fairly represented in the individual member states, but also that there needs to be an overall European effort to improve public awareness of Hard of Hearing people’s communication preferences and needs, since the data shows that Hard of hearing people are still being inaccurately represented by hearing people. It is important to note that Belgium, Austria, Slovenia and Ireland all agree that the needs of Hard of Hearing people are not understood.

Qu.4 Table 3: Are the needs of Hard of Hearing people understood?

Do you think the different needs of hard of hearing people are understood in your country?	Country
Yes	France
No	Belgium, Austria, Slovenia and Ireland
Partially	Finland *, Germany**, Denmark, UK, Hungary, Iceland, Poland, Norway and the Netherlands
Other	Czech Republic

* Both Finish organisations said ‘Sometimes’

** All three German organisations said ‘Sometimes’



Designing of the Services

Question five, asked if Hard of hearing people are included in the designing of the services. 58.82% wrote put 'Sometimes', while 23.53% said 'Yes, but there is no support to participate fully in meetings'. Only 11.76% (2 members) answered yes.

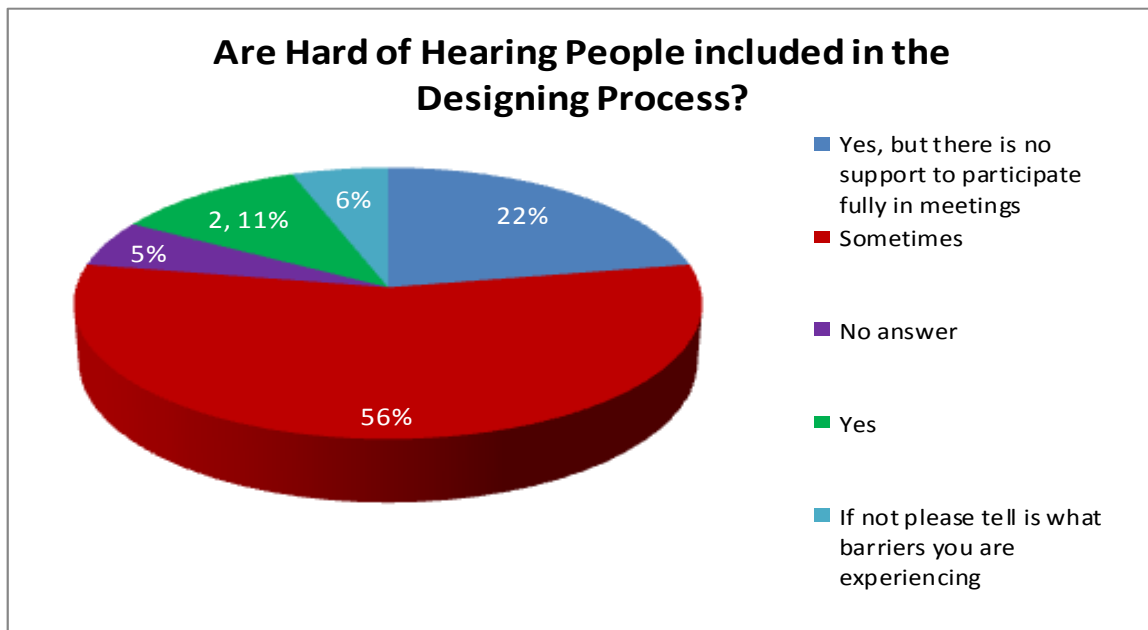
Finland, Belgium, Hungary and the Czech Republic said that they were included in the designing procedures but not given support to participate fully in meetings, which relates to lack of awareness of communication methods once more. One country, Poland, said that they were not included in the designing process at all and that they faced several barriers:

"There are two reasons. The first one is lack of awareness in the society about specific needs of HOH. The second - also very important - lack of awareness among HOH what solution can help them."

In contrast to Poland, the United Kingdom wrote that they were only sometimes included in the designing process which is surprising as we suspected more of a stronger contrast between the two countries. The Polish concerns also brings up a very interesting point that is not only a lack of awareness in society on HoH people's needs, but that HOH people themselves are not aware of solutions or services in existence that can help their hearing. Therefore, more needs to be done to promote and make information as accessible as possible and mobilise and improve the community of hard of hearing people in all European countries.

Qu. 5 Table 4: Are Hard of Hearing people included in the designing services?

Are hard of hearing people included in the designing services?	Country
Yes	Germany (Schwerhörigen), The Netherlands
Yes, but there is no support to participate fully in meetings	Finland, Belgium, Hungary and the Czech Republic
Sometimes	Denmark, UK, Iceland, Austria, Germany (Tinnitus), France, Slovenia, Norway, Ireland
If not please tell us what barriers you are experiencing	Poland



Question six asked if the law in each member’s country understood and explored fully the reasonable adjustments for HoH. 50% of member country’s said no and only 11% (2) said yes. This is concerning as without reasonable adjustment Hard of Hearing people will not be considered equal and will be subject to discrimination in for example the workplace.

Furthermore Austria, Finland and The Netherlands all said that they did not know if the law was clear on reasonable adjustment and that they were also not completely aware what reasonable adjustment entailed. The Tinnitus organisation in Germany, in contrast to the other German organisation that responded to the survey, said that:

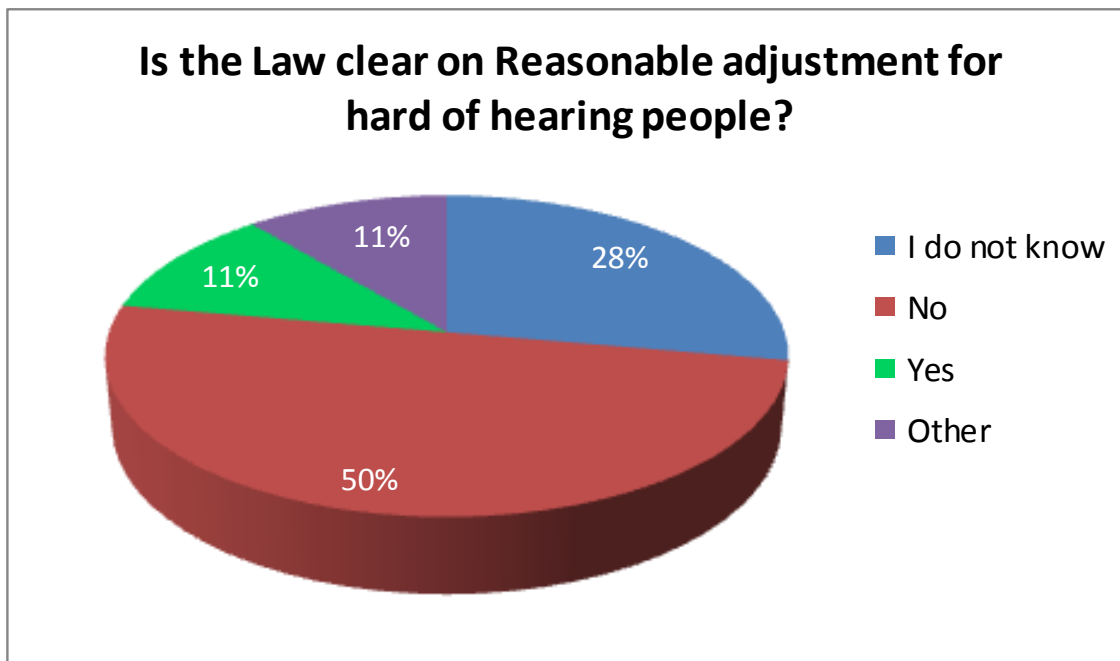
“The German Law is in special points for HoH not satisfactory”. This shows that opinion and general consensus in Germany is widely split.

‘The Czech Republic for Deaf’ people answered ‘Other’ to this question, and said that the law assumed that people who are hard of hearing say what they need. The organisation noted that:

“The Law says that only people with hearing disability say what they need, for example if they need sign language they will have interpreter. So people with disability decide what their choices are.”

Qu.6 Table 5: Is the law clear on what is reasonable adjustment?

Is the law clear on what is "reasonable adjustment" for hard of hearing people?	Country
Yes	Hungary, Germany (Deutscher Schwerhörigenbund)
No	Denmark, Belgium, UK, Ireland, Poland, Slovenia, Norway, Iceland, France
I don't know	Austria, Finland, The Netherlands
Other	Germany (Tinnitus org.), Czech Republic



Forms of Support

Question seven asked respondents what forms of support do HoH people have a right to ask for under the existing law from Government bodies or service providers? This was a multiple choice question so could really show us the different services for each country.

The results are very interesting with: 77.78% adding simultaneous speech to text, 44.44% answering note taking, 83.3% saying sign language interpreters, 77.78% saying hearing loops, 50% noting sign supported interpreters, 61.11% said Portable FM and IR systems and finally 27% said other. No member answered no for this question, so this is positive and

shows that HoH people are getting some support in some of the right areas, but this all needs to be improved so all services are available to all HoH people.

However, Austria answered ‘I do not know’ and did not provide a single example of the types of support in Austria, so a further investigation is needed into this country and area. The UK and Germany have the most forms of support with both adding every option to their response (as seen in Table 6). Finland, Denmark and the Czech Republic also had a high number of support methods which shows that these European countries are the most accessible and best examples of good practise in terms of support that Hard of Hearing people have a right to ask for. It is largely in Western Europe that has the most methods of support legally available. Poland is one of the least supportive countries with only ‘notetaking’ and ‘sign supported interpreters’ available for Hard of Hearing People (See Table 6).

Several countries also clicked ‘other’ as part of their answer.

These were: France that noted that the methods of support they chose were not always available, The Deutscher Schwerhörigenbund e.V., Germany association that said these services were only available *“for first education, social services and public authorities”* and Slovenia who wrote that, *“We have the right to ask, but did not output adjustment (FM, hearing loop systems).”*

Finally, Poland also noted that:

“Sometimes also portable FM or induction loop. The portable FMs are very often adjusted to a specific model of HA so not every HOH can use it.”

Qu. 7 Table 6: What forms of support do you have a right to ask for under existing law?

What forms of support do you have a right to ask for under the existing law from Government bodies or service providers?	Country
Simultaneous Speech to Text	Finland, Denmark, Belgium, UK, Hungary, Germany*, Norway, Ireland, Czech Republic, The Netherlands, France
Sign Language Interpreters	Finland, Denmark, Belgium, UK, Hungary, Germany*, Norway, Ireland, The Netherlands, France, Czech Republic
Hearing Loop Systems	Finland, Denmark, Belgium, UK, Hungary, Germany*, Norway, Ireland, The

	Netherlands, France, Czech Republic
Sign Supported Interpreters	Finland, Denmark, UK, Poland, Norway, Germany*, Czech Republic, France
Portable FM and IR Systems	Finland, Denmark, Belgium, UK, Germany*, Norway, Czech Republic, The Netherlands
Note taking	UK, Poland, Norway, Ireland, Germany (Deutscher Schwerhörigenbund e.V., Germany), Czech Republic

*Both German organisations clicked this option.

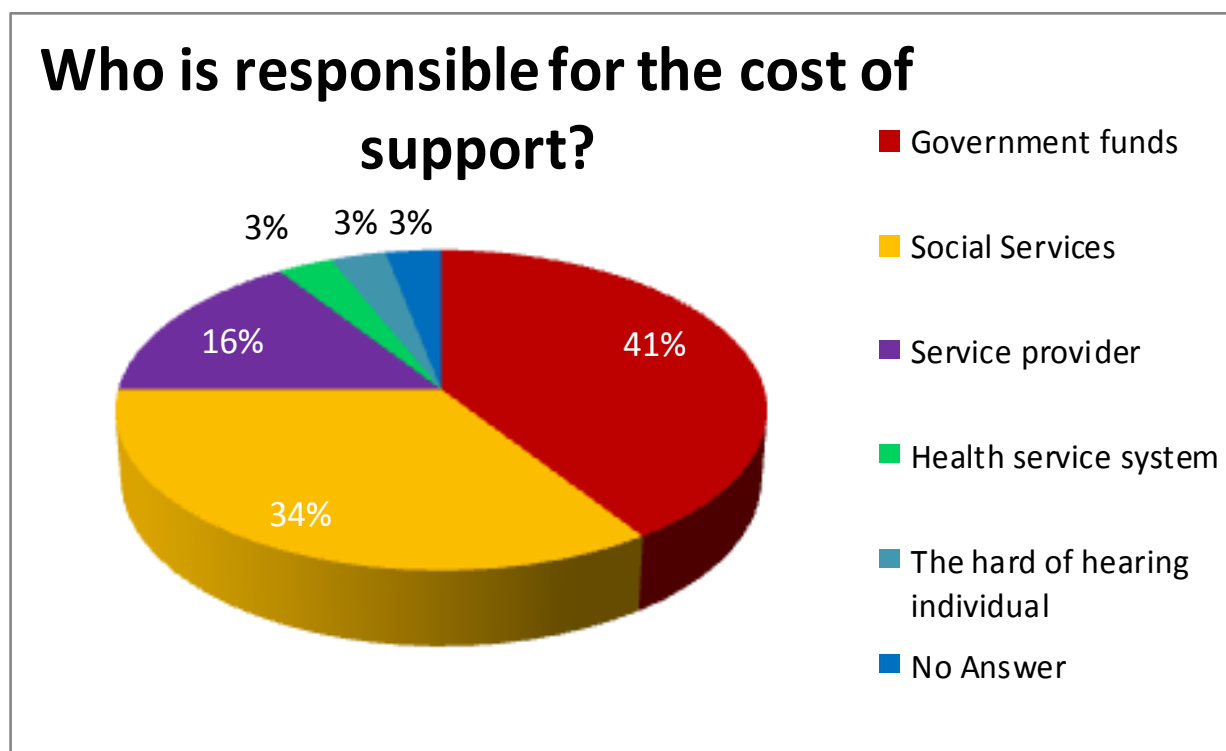
Question eight asked who was responsible for the costs of support, and the largest proportions were 76.47% government funds and 64.11% social services, therefore EFHOH and other HoH organisations and bodies will aim to target both the government and social services when creating future campaigns to improve services in different European countries.

The German Tinnitus association also added 'other' and said that, *"it is complicated to find the right place to get the cost substituted"*. Norway also wrote that, *"It depends on the event and who are responsible for the event."* So the answers for this question were very relative to the context of the event and nature of support. The Netherlands also added that the Health Service System could also be responsible for the cost of support but again this is dependent on context. Comparing Poland and the United Kingdom, the Polish organisation said that government funds are responsible for the cost of support, while the UK notes that social services and social providers can also be responsible for costs. Interestingly Iceland added that often the Hard of Hearing person themselves will be responsible for the cost, which is concerning and shows the worrying trend that Hard of Hearing people are still not considered disabled as this support should be paid for by external bodies.

Qu. 8 Table 7: Who is responsible for the cost of support?

Who is responsible for the cost of support?	Country
Government Funds	Finland, Denmark, UK, Hungary, Iceland, Germany, Slovenia, Norway, Ireland, France, Poland
Social Services	Denmark, Belgium, Finland (), UK, Austria,

	Germany, Norway, Czech Republic, The Netherlands, France
Social Providers	Belgium, UK, Iceland, Ireland
The Hard of Hearing Individual	Iceland
Other	Norway, The Netherlands



Employment Support

Finally, **Question nine** asked, what support can you receive in terms of employment? This was also multiple choices. 55.56% said simultaneous speech to text, 22.22% said note taking, 50% said sign language interpreters, 50% said hearing loop systems, 50% also said Portable FM or Infra-Red system and shockingly 11% (2 respondents, the Austrian organisation and the Icelandic organisation) said that there was no support in their country at all. Though this number is small it a very worrying statistic and more research need to be done in Iceland and Austria into how we can combat this. Unlike Question 7, less countries chose each option which suggests that though the support methods are legally available receiving the support is actually more difficult.

(See next page for breakdown of 'Other' responses)

Employment Support: 'Other' responses

8 organisations also checked the 'other' box and have added further details about the support systems in terms of employment which is analysed in below.

The main issues that need to be addressed in terms of the 'other' responses are: ensuring that member states give Hard of Hearing people the right support, for employment support to be regulated, organisations in member states made aware of their responsibilities to their employees who are Hard of Hearing people and in general full assistance for Hard of Hearing people in terms of employment (Please see next page for more details).

Full 'Other' Responses':

Slovenia: *"CI user, or HOH (80% and up on Fowler scale) FM Systems."*

Poland: *"I am afraid we don't have any regulation about it so it depends on good will of the employer. Sometimes they help to buy HA."*

Ireland: *"We have to ask for support and don't always get it, due to failure of employers and officials to understand and empathise."*

Czech Republic: *"Problem is that sometimes employment is not a social service and organization must it pay from own. It's a problem because organizations usually pay nothing."*

Finland: *What does note taking mean and be different from STT? In either writing method the print is not available. Text is used as signed interpretation. It is in the situation only.*

Austria: *There is no assistance: "I live in Austria and we are able to get an ID that labels us as special needs if we have little or no hearing. There are some benefits but also lots of preconceived assumptions from what I could tell. I was told not to get that ID as it my limit my freedom to drive...whether that is true or not, I don't know."*

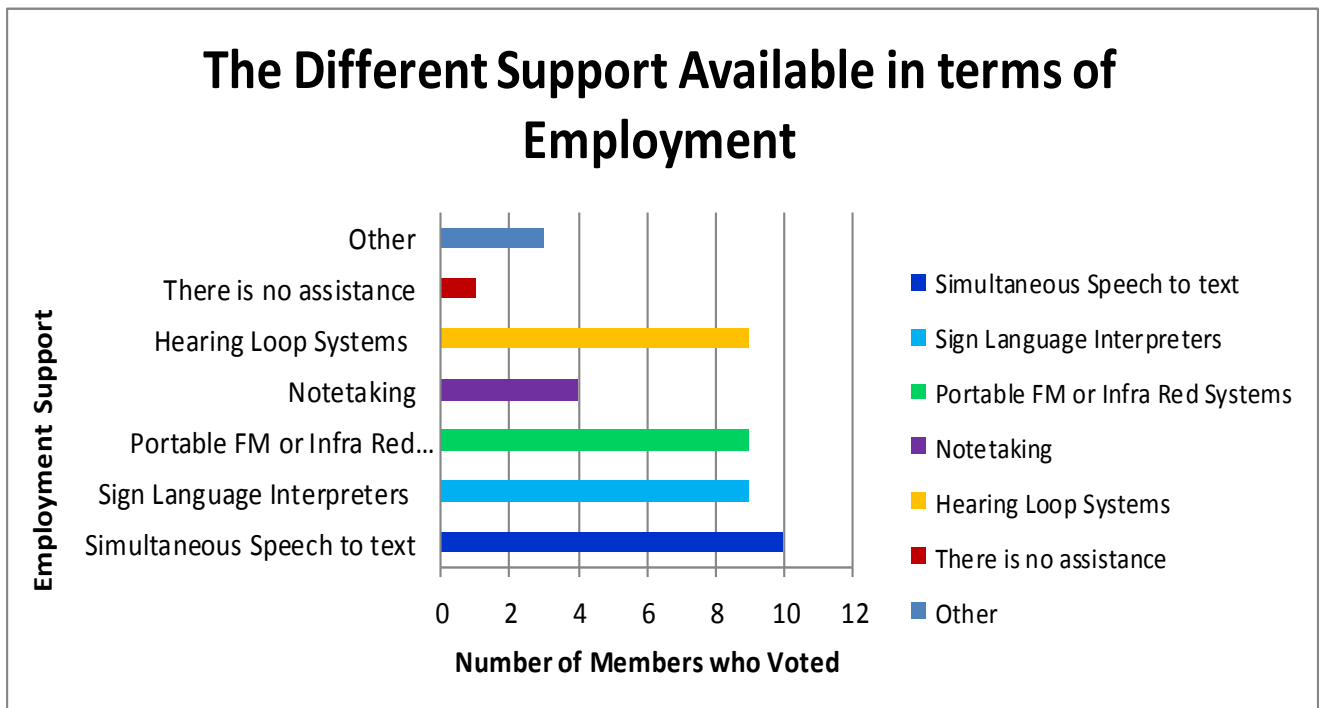
Norway: *"In Norway we have a Help Central that can check your work place when it comes to what kind of assistance or facilitation you need. Examples like a facilitated office, carpets on the floor, different technical equipment. It is paid by the government."*

(See next page for Graph and Table 8)

Table 8: What support can you receive in terms of employment?

What support can you receive in terms of employment?	Country
Simultaneous Speech to Text	Finland, Denmark, UK, Hungary, Norway, Germany*, The Netherlands, France
Sign Language Interpreters	Finland, Denmark, UK, Hungary, Slovenia, Norway Germany*
Hearing Loop Systems	Finland, Denmark, Belgium, UK, Norway and France
Portable FM and IR Systems	Finland, Denmark, Belgium, UK, Norway, Germany*, The Netherlands
Note taking	Denmark, UK, Norway, Germany*, Czech Republic
There is no assistance	Iceland, Austria

*Both organisations added this option



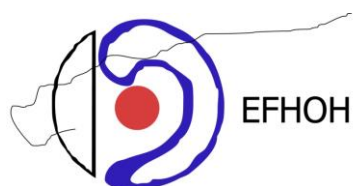
Conclusion

In Conclusion, the survey that we as EFHOH have conducted has revealed some interesting trends and areas that need further improvement. Although the survey did not originally aim to identify the public's impression of Hard of Hearing people, the results show that hearing people are consistently generalising the needs of those who are Hard of Hearing and further public awareness is needed to correct this. Furthermore, there were some clear trends with the Scandinavian countries, specifically Finland and Denmark, whose answers mimicked each other for nearly every question. This shows us that geographically the legal system and understanding of Hard of Hearing people's rights are similar. Germany and the United Kingdom have similar approaches to the legal context, with the rights and needs of these two countries understood in a similar positive way.

Poland and Australia are shown to be the countries with the worst practices along with the most barriers, issues and lack of support methods. The Austrian response in general shows a lack of understanding and knowledge of support systems and their rights in general from both the member state itself and also the organisation itself. Therefore more needs to be done to ensure the government/ states but also Hard of Hearing people themselves are fully informed on these issues.

Some general conclusions can also be drawn that would be applicable to all member states and European understanding of Hard of Hearing as a whole. First of all, more needs to be done to improve awareness of the disability and the different communication methods involved. This would avoid generalisations and discrimination towards Hard of Hearing people. Further clarification of the law is also something that all member states must address to ensure that all of forms of Hard of Hearing are treated as disabilities (protected through the UN CRPD) and once again decrease generalisations that prevent member states from being equal.

April 1st 2016



European Federation of Hard of Hearing People