

European Federation of Hard of Hearing People

Experiences of late
deafened people in Europe

2018 Report

EXECUTIVE SUMMARY



Dear Reader,

We are pleased to share the European Federation of Hard of Hearing People (EFHOH) report which is a result of our recent collaboration with our member, the National Association of Deafened People in the United Kingdom.

In 2014, the EFHOH AGM mandated a new working group known as the **Late Deafened Working Group**, charged with advising the EFHOH Board on the current situation of late deafened people in Europe. As deafened people face unique challenges, we wanted to capture their views with a survey, on which this report is based.

The aim of the new survey was to collect deafened peoples' responses relating to their experience from all countries within Europe to provide a broad understanding of how support is attained in different countries, what the barriers in different countries are, and the impact of hearing technology on an individual's quality of life.

Late deafened people often had normal hearing until the age that they started to lose their hearing progressively or suddenly which can vary greatly. They will rely predominantly on visual forms of communication during this time. It can be difficult for them to adapt as they have had no previous experience of deafness and are often not sure where to ask for help.

In the survey we have made a clear distinction between sudden deafness and progressive deafness as they are different experiences of hearing loss, though both result in similar adjustment difficulties for those affected.

We hope this report will provide complimentary insight and spark a potential interest in the subject. As we will explain further, professionals in audiology and mental health departments need to recognise the unique problems of deafened people to support them in the change of circumstances they are going through. Additionally, support infrastructures need to be in place to enable the continuation of their education, employment and quality of life. Doing nothing is not viable as the cost to society as well as wellbeing of an individual is not something that can be ignored.

We would like to express our thanks to all who took part in the survey.

Lidia Best and Darja Pajk | European Federation of Hard of Hearing

WHO ARE THE DEAFENED PEOPLE?

There is a distinct lack of understanding related to deafened people and their unique needs. The first international survey of deafened people took place in 1996 while this survey is the first one, undertaken by the European Federation of Hard of Hearing People.

Judith A.Viera, who conducted a worldwide survey on the instructions of the IFHOH Board, attempted to answer this question in 1996 by conducting the survey in Austria, Finland, Denmark, Poland and the Netherlands. Another task was to determine which community deafened people belong to: Deaf or hard of hearing.

In the report she concluded, based on the answers that deafened people have a strong alignment with the hard of hearing community.

The unique position of deafened people has also been made clear in Judith's conclusions:

“There are two factors that together make deafened people different from those who are born deaf or who are hard of hearing:

- 1. People who are deafened are unable to hear and understand spoken word, even with hearing aids and other forms of amplifications (ALD's). People who are deafened must depend more or entirely on visual forms of communication rather than amplification.*
- 2. The deafened individual will have been able to hear and speak normally earlier in life, especially during school years”*

The report was written in 1996, at the time the cochlear implants were still relatively new and often not available to deafened people on national health or medical insurance provisions. In many countries in Europe the situation has changed thanks to national health/insurance provisions and technology improving enormously. Hearing technology now allows deafened people to access sound and improve individuals' quality of life.

Many deafened people will continue to identify themselves as hard of hearing since implants have proven to be a good benefit to many by allowing them access to sound. The differences between deafened and hard of hearing people are now not so distinct. Nonetheless, deafened people still depend on the visual communication identified above as they cannot understand speech well enough. Many continue to rely on speech to text (captioning).

This report will examine a wider overview of the employment, education and access to health for deafened people.

THE RESULTS

The European survey took place between December 2016 - February 2017 in cooperation with the National Association of Deafened People and EFHOH interns.

Country	Online responses
Cyprus	2
Czech Republic	2
Denmark	100
Estonia	11
Faroe Islands	1
Finland	7
France	19
Germany	67
Greece	15
Ireland	2
Jersey	1
Latvia	3
Netherlands	9
Norway	6
Poland	3
Slovenia	4
Spain	2
Sweden	33
Switzerland	7
United Kingdom	50
Total	344

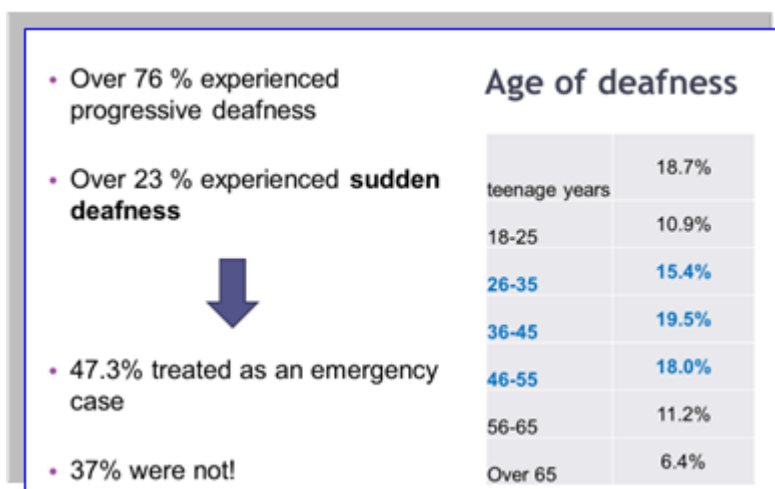
The online survey attracted **391** participants from **21 countries** with answers mostly from the UK, Denmark, Estonia, France, Germany, Finland, Greece and Sweden. We have also received an additional **11 paper** copies from Finland, although 47 people chose not to include their country of origin making it impossible to tally them in countries responses.

This survey was written in English only (due to restraints on our resource, we were unable to distribute translated surveys) and distributed widely across Europe.

The countries that did respond in large numbers were the United Kingdom, Denmark, Estonia, France, Germany, Finland, Greece and Sweden. The respondents to the survey were mostly female (66%) which is not reflective of accepted gender based hearing loss numbers, which suggest that hearing loss has no notable gender bias (some reports

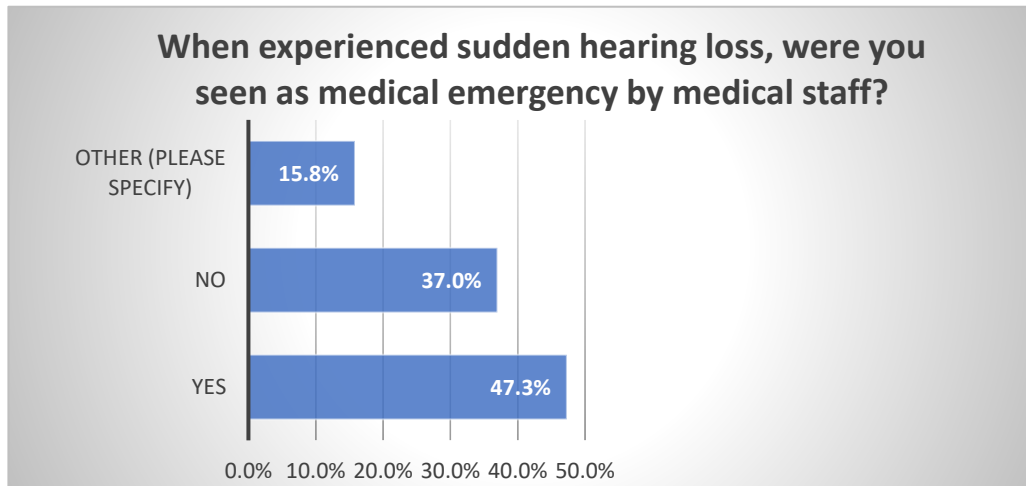
suggest that hearing loss is actually more prevalent in males¹). 70% of participants were aged 46 or older and 26% were aged 65 or over.

We asked the age when they became deafened. The results were startling, the age of deafness was the most productive years for vast majority and this survey suggests that hearing loss is an issue that affects a number of people during the prime working years of their life.



AUDIOLOGY

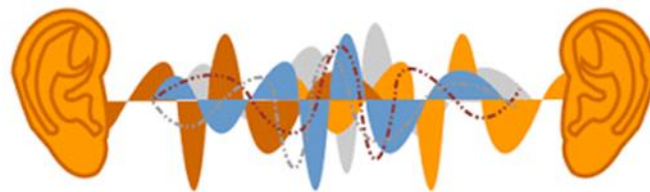
We asked if the deafness was sudden or developed over some time, with the majority experiencing progressive hearing loss over some time and 76% reported progressive hearing decline (a few weeks or more) as opposed to 23% who experienced sudden hearing loss (within 24-48 hours).



We wanted to know if when the person experienced sudden deafness, were they seen as an emergency? By this, we expect that deafened person's cause of sudden deafness is dealt with within 48 hours.

From this survey, just 47% of people reported having their hearing loss treated as a medical emergency and 37% of respondents who experienced sudden deafness were not seen as an emergency, meaning the vital window for intervention was missed.

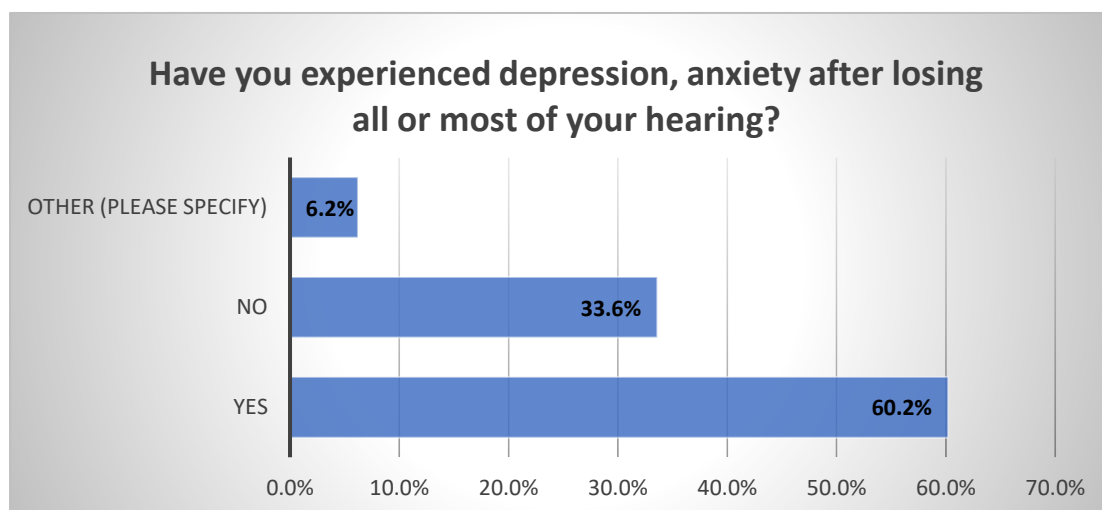
It was also surprising to learn that 22% of respondents were not seen by an audiologist and 11% had to ask for it. Only 35% were seen immediately.



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MENTAL HEALTH

Dealing with gradual or sudden change will have an impact on an individual and the immediate family. This is why we asked questions related to mental health. Our survey mirrors previous results from research in France with our member Bucodes taking part ¹ indicating a direct causal link between hearing loss and mental health. Many respondents to the French survey viewed the experience of hearing loss, especially sudden hearing loss as **a traumatic experience**.



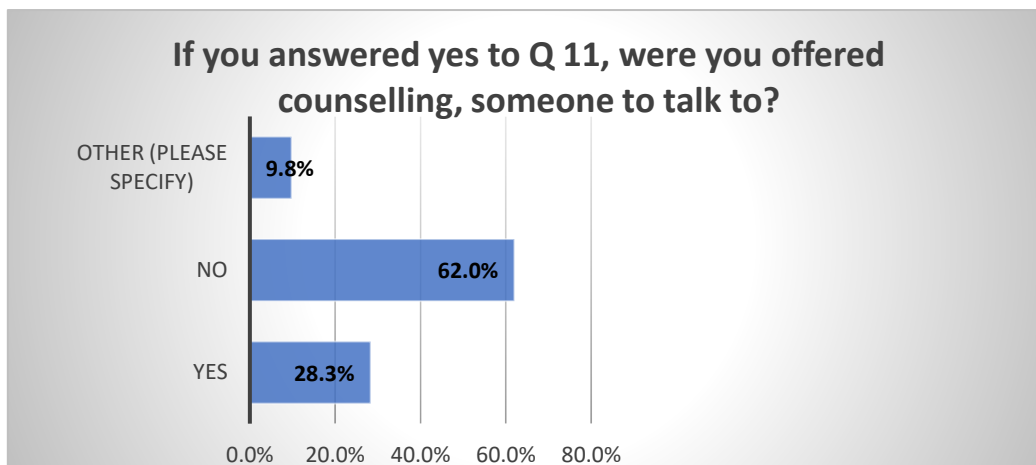
60% of our responders confirmed feeling anxiety and depression following the event of progressive or sudden hearing loss.

Considering the [WHO suggests that mental illness statistics are often underestimated](#) ² and underreported, the 60% figure reported by respondents to this survey may only be providing a 'low' estimate of the true number of people experiencing mental health problems after experiencing hearing loss.

¹ <http://inpes.santepubliquefrance.fr/CFESBases/catalogue/pdf/1717.pdf>

² <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/data-and-resources>

More worryingly however is the reported state of mental health support. Of the 181 people who replied to have experienced mental health problems following their hearing loss, 120 of them responded that they had not been offered psychological care and support. This should be a real cause for concern.



Most respondents to the survey demonstrated that they were not offered any form of mental healthcare. The anecdotal evidence shows a lack of awareness for how hearing loss affects an individual but it can also lack the awareness of how to provide counselling in an effective manner with communication as the main barrier to provision.

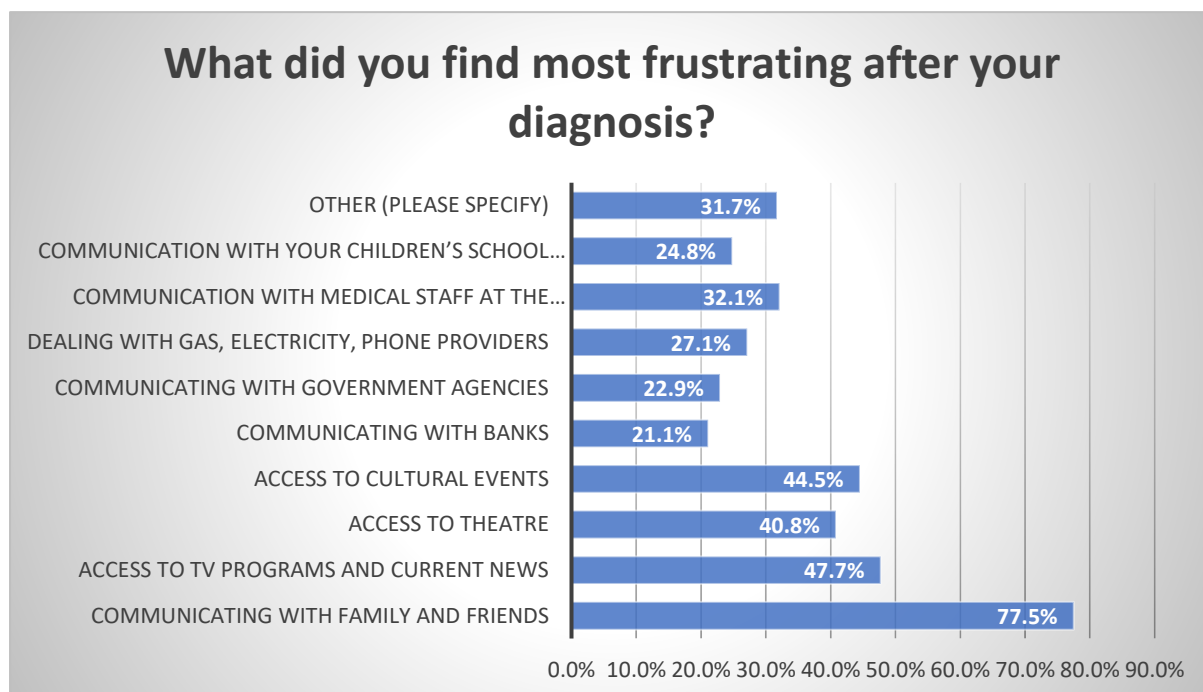
We came across an interesting comment, where the respondent reported that they were forced to decline an offer of counselling support due to the *'lack of information regarding how they would communicate with the psychologist'*.

Access to communication in the situation when one cannot hear any longer is vital for deafened people, the majority require access to spoken language in text alternative. Clear communication and presenting information in accessible way would be a simple and effective solution.

ACCESS TO COMMUNICATION

As the communication is vital to inclusion, participation and independent living, we wanted to learn what the most common causes of frustration were. Family and friends were the hardest to deal with (77% reporting great difficulties), followed by access to TV at 48% and theatre, social events at around 40%.Worth of note is the 30% of respondents who have found communication with medical staff most frustrating.

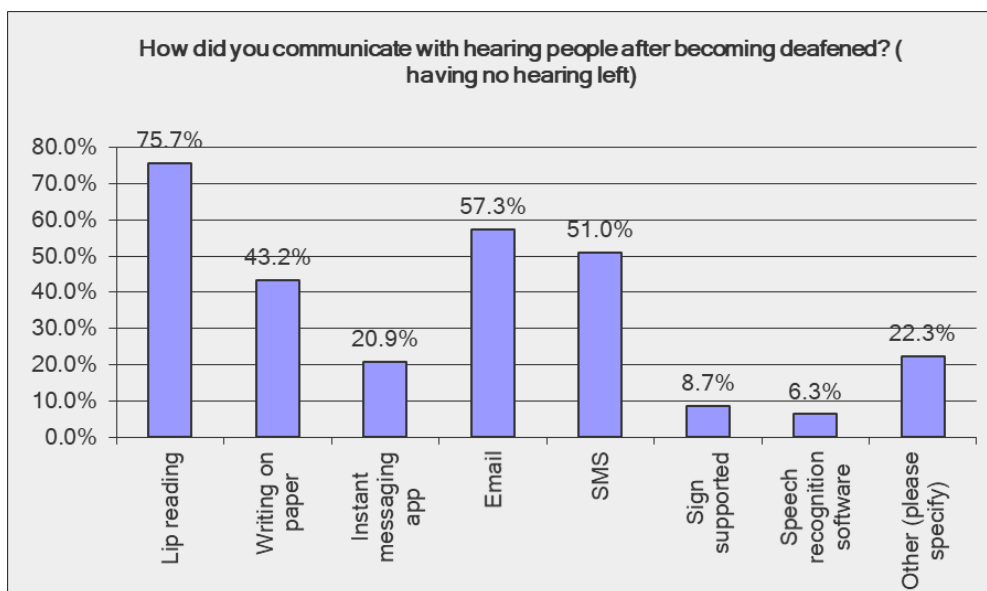
Since access to healthcare is enshrined in the United Nations Convention on the Rights of Person with Disabilities (CPRD) Article 25 we believe the issues need to be taken seriously by those responsible.



Keeping with the topic of interactions, we wanted to learn what strategies were used to keep communication going. How they communicate? Could they use speech to text support? We asked multiple choice questions, **“How did you communicate after you lost hearing?”** Lipreading (also known as speechreading) was often mentioned by 75% of our respondents. Yet, we know that lipreading is a skill that needs to be learned and all too often is used in case of a lack of professional support such as speech to text (captioning), relying on lipreading alone is not adequate for some deafened people as explained in the DCAL review³.

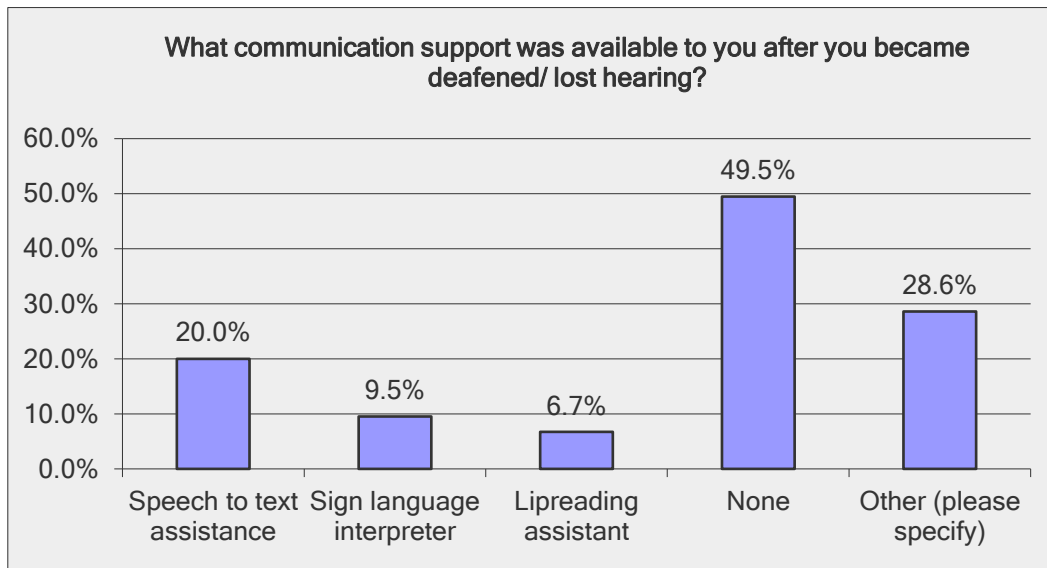
Using new technology such as emails, instant messaging and SMS as well as speech to text were also options given.

Looking at the results, sign supported language (based on spoken language grammar, not to be mistaken with sign language) was used by only 8% of respondents as support in communication. This should not be surprising - after all, deafened people have developed and learned spoken language as their first and main language or sometimes other languages throughout their mainstream education and they require access to their own language in the form of text, such as subtitling on all audio-visual media and live captioning/ speech to text to fulfil the obligations of Article 9 (Accessibility) of United Nations Convention on the Rights of Persons with Disabilities (CRPD).



We also noted the lack of information about available support. Deafened people are most at risk of missing on vital information and 49% of our respondents reported no access to communication which is concerning.

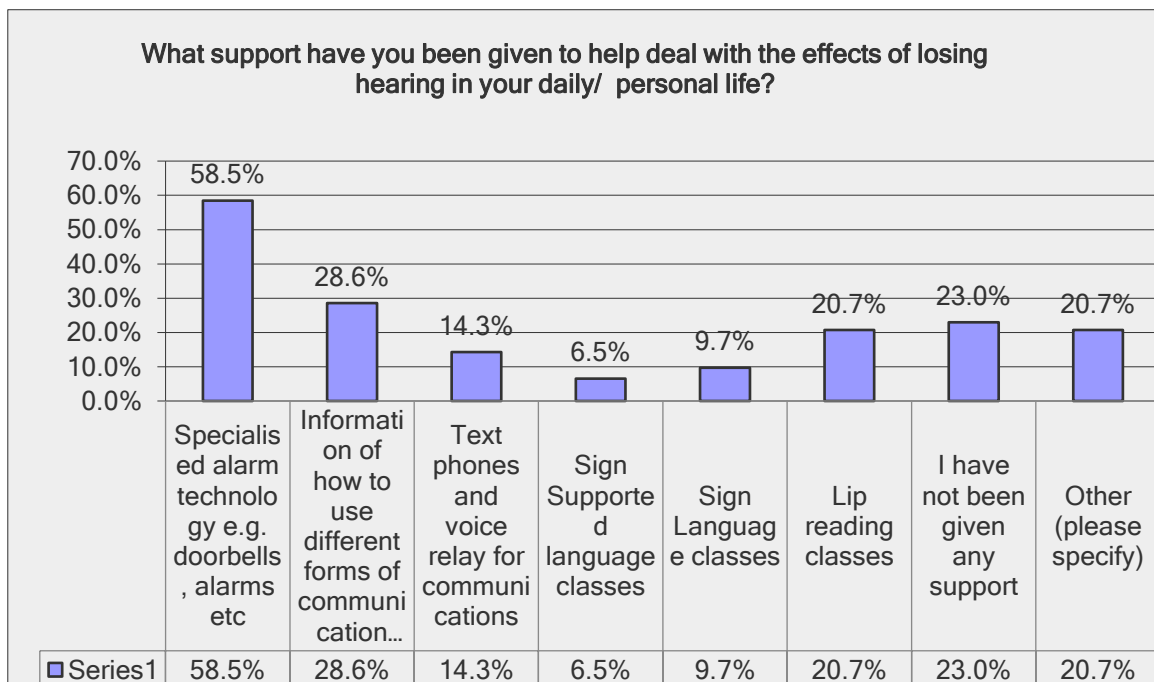
³ <http://discovery.ucl.ac.uk/1347961/1/speechreading%20for%20information%20gathering.pdf>



The only consistently available support for people that is reportedly available is technological e.g. specialised alarm systems (59%). This could indicate that the support people are receiving, although potentially helpful, does not help in combatting their most pressing concerns.

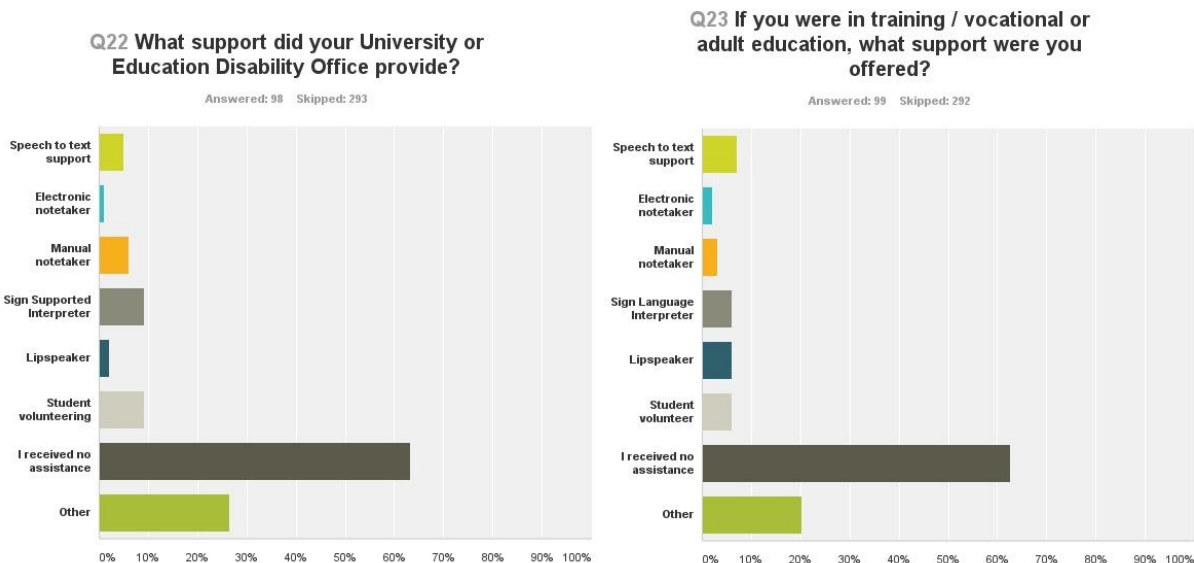
When people were offered communication support it was often financially supported in some ways. Unfortunately, 20% of respondents reported being offered no support in payment for the support required and 19% reported being offered partial support, making it likely that they were still priced out of the support that they needed to stay independent.

However, 61% of people were offered the full financial package for their support in countries with high level of government initiatives such as the UK and Nordic countries leading in their positive responses.



EDUCATION AND TRAINING

Our survey reported some worrying indications regarding the support in education and lifelong learning for deafened people. Of the 98 individuals who replied to questions regarding the type of support received whilst a student, over 65% of people ultimately reported receiving no support from their university. These figures are also mirrored for people with hearing loss undertaking vocational training – of the 99 respondents, over 65 (approximately 65%) reported receiving no support or having no support available during their training in direct opposition to the IFHOH position paper published regarding education in 2014.



Over 30% of people who undertook our survey lost their hearing during or before the age of 25 (the age bracket in which the highest numbers of people attend further education).

This means that the issue of educational support for deafened and hard of hearing people must be a considered one that affects a significant number of people. That approximately two thirds of people who attend university do not receive any support clearly indicates that people with hearing loss are not receiving the same rights regarding access to education.

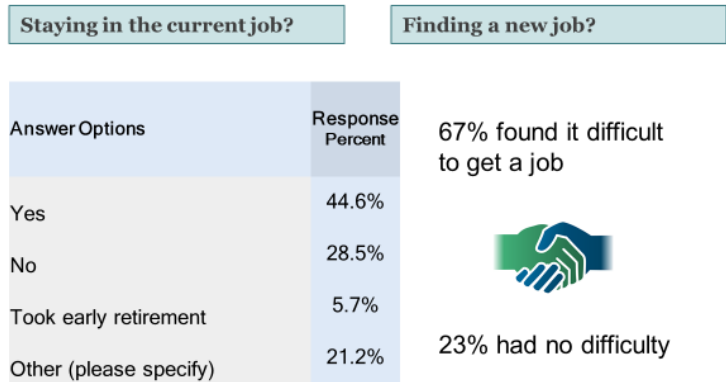
There are people reporting that speech to text, student volunteers, notetaking software, lipspeaking assistance and other forms of support were made available for them provide evidence that there are solutions to the problem of equal access, and it is important to recognise good support provision but more needs to be done.

EMPLOYMENT

In our survey 66% of respondents are either employed or have been employed since their hearing loss diagnosis (although almost half of the total number of people taking the survey choosing not to answer this question suggests that this number is an inflated statistic, and that the true proportion of people who have worked post hearing loss is smaller). In any case, of the same sample only 45% of people could keep their job after experiencing hearing loss.

This means that over half of respondents do not have adjustments made that will allow them to continue in their role.

Our respondents who have searched for a new role since being diagnosed (85 in total) have overwhelmingly reported facing additional difficulties. 67% of people have reported finding it difficult to find a new position and many of them have reported really concerning comments as to the source of their difficulties.



*Potential employers cannot look beyond your hearing devices, you are labelled as deaf and cannot hear a thing. The potential employer does not look at your talents or what you **can** do' – Netherlands*

Interviews are high pressure situations at the best of times but having to cope lip reading new people... is incredibly difficult. It made me feel awful and I used to leave the interview and cry on the way home' – United Kingdom

Our survey here is certainly suggesting that deafened people are finding it difficult to stay in employment as well as gaining new jobs, and that employers and interviewers may not be making and anticipating reasonable adjustments on a regular basis across Europe. The responses mirror other surveys such as one conducted by the TotalJobs employment agency in 2016 ⁴.

⁴ <https://www.totaljobs.com/insidejob/deaf-jobseeker-employee-report-2016/>

PEER SUPPORT

Peer support is essential to person's wellbeing, finding like-minded people who have lived experiences to share as well as practical guidance.

It was encouraging to see the majority of respondents have been supported in finding deafened people and had opportunity to connect.

The organisations for hard of hearing people scored highly as offering peer support, many also took to internet finding answers. This was followed by equal number finding deafened peers via deafened associations, deaf associations or via audiologists. There are few independent associations for deafened people in Europe so it is not a surprise when 25% of responders have not met deafened people yet.

PROVIDING INTERVENTIONS

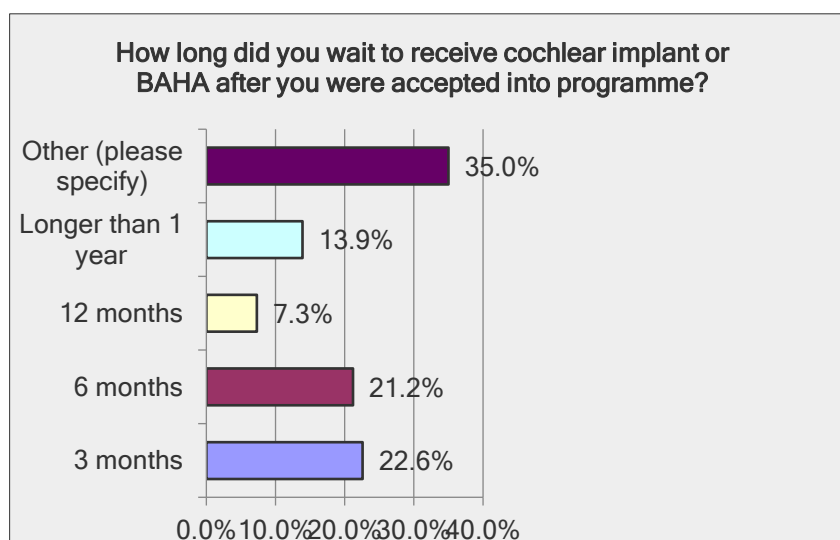
The last part of our survey looked at possible interventions and if they were offered. We were keen to find out what interventions were suitable, how long they waited and how they changed respondents lives.

80% of our respondents were offered hearing technology to help them with 7% deemed not suitable and 5% not offered at all.

Of the solutions offered, 121 were offered hearing aids and 84 were offered cochlear implants with 2 people offered auditory brainstem implant, 2 have BAHA and one was offered vibrotactile hearing aid.

Looking at the waiting time, 44% waited between 3 to 6 months, 7% had to wait a year and surprisingly 14% waited more than a year.

When we asked about satisfaction with solutions, the majority rated the intervention between 6-10 out of 10 and average score 6.5 for satisfaction.



MOVING ON AND ADAPTING

Our last question “*How do you communicate now?*” related to the ability to interact socially and with family after the interventions and it is clear that offering hearing technology has helped the majority. Not everyone could benefit from hearing technology interventions and they still require ongoing support and reasonable adjustment.

It has also shown how diverse deafened people are in adapting to their situation and what they found useful in everyday life. An overwhelming majority of 87% use hearing technology that they were offered. This is a great testament to interventions being effective for the majority of deafened people. It is also interesting how deafened people use different strategies to support their daily communication with others. It is important to note that lipreading can be effective for many people when used in combination to access to sound as lipreading is guesswork and it’s required to learn the skill. However lipreading can be useful as an additional form of visual support in daily communication with family and others.

The speech to text support is still used by deafened people, even after implementation to support access to public events, meetings and education. Unfortunately not many countries have developed the training for professionals and this may reflect on the answers we have seen in the report.⁵

Answer Options	Response Percent
I use my hearing technology as above	86.7%
Speech to text support	14.4%
Lip reading	61.5%
Sign supported speech	5.6%
A mixture of sign supported speech and lip reading	13.3%
Sign language	9.7%
Mouth Hand System	1.0%
Fingerspelling alphabet	8.2%
Cued Speech	0.0%
Written Communication in the form of notes	16.9%
I still find it very difficult to communicate at all	13.8%
Other (please specify)	10.3%

⁵ <https://efhoh.org/wp-content/uploads/2017/04/Birgit-Nofftz-Germany-2014-Speech-to-Text.pdf>

CONCLUSIONS

Our research findings strongly indicate that the variety of support provided to deafened people is not adequate in many countries indicating a lack of understanding in regards to their unique needs. Throughout the report we have found big variations in support between countries. Those variations often persist and EFHOH is keen to work together with organisations across Europe in order to improve the situation of deafened people.

We have noted barriers to employment which are both related to attitudes of employers as well as a lack of government initiatives, support available and ICT innovation in place allowing for much better accessibility in the workplace. More needs to be done to combat the issues of underemployment as well as a lack of reasonable adjustment at work.

This suggests that as well as a social and healthcare issue, the prevention, treatment and care of hearing loss should be considered a vital economic one – demonstrating the importance of WHO's 'World Hearing Day' message that investing in hearing loss and deafness is a sound investment.

Across Europe our survey suggests that hearing loss does not receive appropriate medical treatment when it first occurs. This might point to disjointed actions between medical agencies and what the appropriate steps and level of concern should be. Even more concerning is over 60% of people experiencing these issues were not offered any form of counselling or therapy to cope with their situation. This could suggest that there are some very important aspects of the trauma involved in hearing loss that are still largely ignored.

We finish the conclusion with more positive news as it became clear that hearing technology interventions are decidedly beneficial in supporting the quality of life of many deafened people.

POINTS TO TAKE FORWARD

- Majority became deafened during their employment years (wasted productivity)
- Low level of awareness of deafened people needs in many countries
- The impact of becoming deafened is still not taken seriously enough
- Urgent need to increase communication professionals to support deafened people such as real time text.
- Need to develop dedicated support network, access to information and helping deafened people to live independently
- Access to assistive technologies at workplace which are vital to stay at work and to gain employment should be encouraged
- Need for inclusion of deafened people specific needs in the health, education and employment policies.
- Hearing technologies should be offered as part of national health as an effective intervention.
- Need for national surveys to identify potential gaps in support provision

ABOUT EFHOH

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/>

ABOUT LATE DEAFENED WORKGROUP

Current membership of the Late Deafened Workgroup

BUCODES (France)

National Association of Deafened People - NADP (UK)

Stichting Plotsdoven (Netherlands)

Zveza Drustev gluhih in naglusnih Slovenia (Slovenia)

Kuuloliitto r.y. (Finland)

Vuxendöva i Sverige- VIS (Sweden)

Siketek es Nagyothallok Országos Szövetsége – SINOSZ (Hungary)

Nagyozhallók és Barátaik Országos Közhasznú Egyesülete – NABOKE (Hungary)

Deutscher Schwerhörigen Bund e.V. – DSB (Germany)

Høreforeningen (Denmark)

For further information, contact EFHOH secretariat at secretary@efhoh.org