



Access to Communication for All

***State of communication support for
deaf people in the UK***

REPORT 2013

Preamble

There are statistics that show there are more deaf people who use speech, lipreading, hearing aids and cochlear implants in the UK than ever.

For the United Kingdom those statistics come from the Action on Hearing Loss website- it is 10 million in 2011 projected to increase to 14.1 million by 2031. 800,000 people (according to AOHL) are profoundly deaf and this group will be unable to hear on the telephone or be able to understand without needing to lipread what is being said.*

Deafened and Hard of Hearing people are dependent on different communication professionals – lipspeakers, notetakers (manual and electronic) and Speech to text reporters, like Jack Ashley used when he, himself became deafened. They are also dependant on people around them using clear speech and being aware of the impact of background noise on listening as hearing aids amplify all sounds, not just the ones you want to hear.

As recently as April this year WHO released their statement relating to deafness **, stating that around 15% of the whole population has a hearing loss. This percentage is rising with an ageing population, and we need to ensure that services to support this group are present for the future



Reference:

*<http://www.actiononhearingloss.org.uk/search.aspx?qcs=how%2bmany%2bprofound%2bdeafness>

**<http://www.who.int/pbd/deafness/news/Millionslivewithhearingloss.pdf>



Access to Communication for All

www.pardongroup.org.uk

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Executive Summary

There is a huge need for support services for so many deaf people who use English. This group is suddenly realising their rights to access information and communication through captions, Access to Work, availability of communication professionals.

This includes access to police, NHS, GPs, HMRC, the arts, community groups, to prevent discrimination, isolation and the associated mental health issues that comes with profound hearing loss.

It is not a solution to tell this group to learn a sign language –when you have lost your hearing, on top of the bereavement feelings (you cannot just call a friend and have a chat on the phone, you cannot just go to a music concert and listen, you cannot go to the cinema and enjoy a film whenever you feel like it, you cannot just go and do yoga classes or join the local history society because you can no longer hear well enough) Your family, friends, colleagues and people you meet daily will not know it anyway.

This deafness has radical, far reaching effects in all areas of life. Everything which once was normal is now hampered by communication problems. It's as if your world collapses. Many people become extremely isolated.

Many of our members **on Pardon** hide their hearing loss until it becomes impossible to hide anymore. They are frightened they will lose their jobs, they are not following their GP they are struggling to deal with professionals who do not have adequate training in deaf awareness or communication skills.

This report is trying to bring to attention the deficiencies in support, lack of training opportunities and qualifications for communication support professionals who can deal with English users and a wider understanding of human rights for deaf, deafened and hard of hearing people in the UK.

Definitions puzzle

Hard of Hearing people is the term that 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. They use English, with help of hearing aids, Cochlear Implants and lipreading.

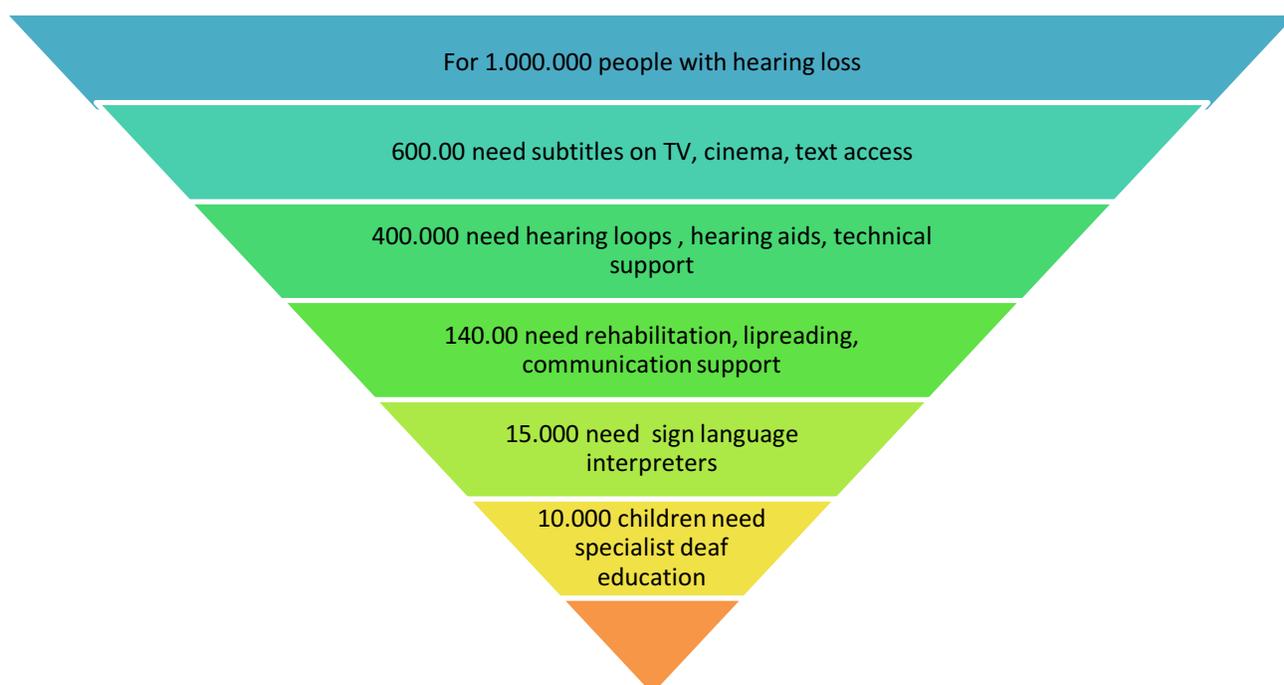
Deafened people are those who have lost all or most of their useful hearing, after acquiring speech. The impact of becoming deafened is soul destroying and there is little or no support in the NHS for dealing with the sudden loss of hearing. This group is finding it very hard indeed to find themselves in new reality with no reliable information about support and more importantly about their own rights. Sudden deafness can basically happen to anyone, at any age. Known causes are meningitis, a tumor, an infection, a traffic accident or a fall from a staircase. However, more often than not, the cause of sudden deafness is unknown.

Deaf people are those who are mostly pre-lingual deaf or who have acquired sign language as their main form of communication. They are also part of distinctive Deaf Community.

Those definitions have been agreed in the international agreement between World Federation of the Deaf (WFD) and International Federation of Hard of Hearing People (IFHOH) during Tokyo Convention in 1991.*

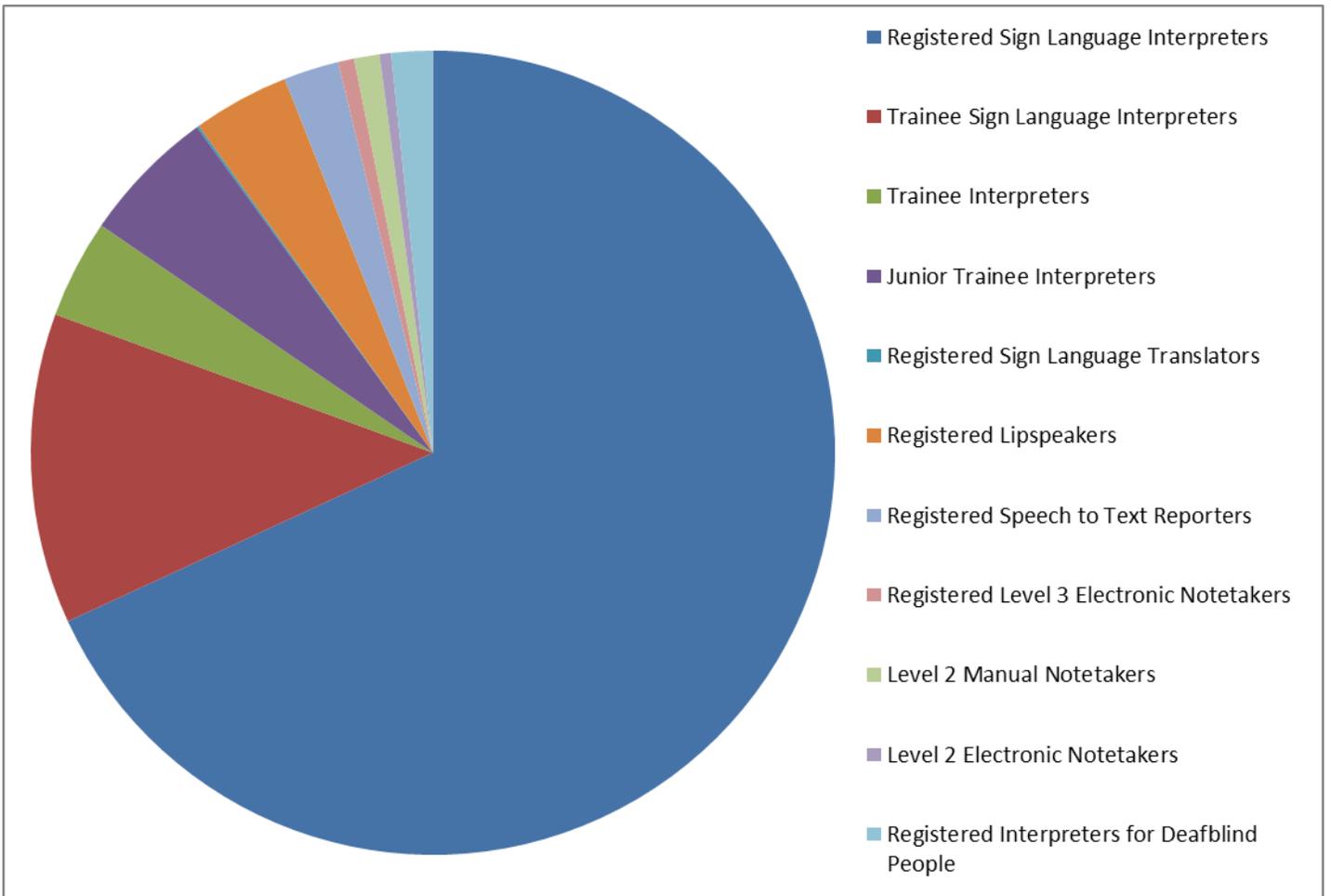
* Annex 1

Hierarchy of needs in the group with hearing loss *



*Model developed with help of Swedish Hard of Hearing Association Hörselskadades Riksförbund (HRF).
See Annex 2

Distribution of communication support in UK



The numbers of registered communication professionals at 31 July 2012 are:

The numbers of registered communication professionals at 31 July 2011 and 31 July 2012 are		% of total	Language supported
Registered Sign Language Interpreters	737	68.1	BSL
Trainee Sign Language Interpreters	135	12.5	BSL
Trainee Interpreters	43	4.0	BSL
Junior Trainee Interpreters	59	5.5	BSL
Registered Sign Language Translators	1	0.1	BSL
Registered Lipspeakers	42	3.9	English
Registered Speech to Text Reporters	24	2.2	English
Registered Level 3 Electronic Notetakers	7	0.6	English
Level 2 Manual Notetakers	11	1.0	English
Level 2 Electronic Notetakers	5	0.5	English
Registered Interpreters for Deafblind People	18	1.7	English

Reference:

http://www.nrcpd.org.uk/news.php?news_id=45

Case studies

London NHS CI clinic provides BSL interpreter to patients going through CI assessment.

Another patient who does not know BSL had her granddaughter typing on laptop to enable her to communicate with doctors.

When asked, the family was not aware that they were entitled to communication support at all.

HoH parents were going through the process of SEN for their child. For the meeting where the SEN was to be finalized they asked for speech to text reporter or electronic notetaker to support the communications.

The Council SEN department refused and it took 3 weeks of constant fighting to ensure that communication support is available.

Council staff used the excuse of the fact that they are able to determine themselves what family needs for communication support despite receiving clear request.

After receiving redundancy with no notice period Norman became very depressed, his GP felt that counseling sessions would be good therapy for Norman.

The counselor clearly did not understand how deafness is affecting Norman and without consulting, removed him quickly from his session stating that he just needs a new job to feel better.

His GP decided to refer him to Sign Health, after a while GP received a letter informing him that due to the fact that Norman doesn't sign, he can't access the services.

Where Norman can go to receive "deaf aware" services?

Both parents are deaf and use speech to communicate. Their younger son was diagnosed with Aspergers in January 2013.

They received invitation to attend advice classes at WLMH in March 2013. The meetings were to start in April. The letter inviting them asked if they need BSL interpreter. They wrote back that they need speech to text reporter.

Organisers did not understand the request and were unable to provide support via Language Line (NHS contractor).

Eventually, after a few months the family was offered next available group meetings in ...October 2013.

Conclusion

The needs of deaf and HOH people are diverse.

We listen if we have residual hearing, we lipread, we use body language, gesture and facial expression. We may use hearing aids, including CI and BAHA. Some of use a sign language like BSL but most will use other communication methods such as speech to text, lipspeakers, personal listeners/loops, communicator guides, cued speech and more. All seem to have issues with Access to Communication whether it is for work or for social purposes that we need to address as a group. There are many other issues in access to services, information and facilities that also need to be debated and acted upon.

We ran a short survey *of mainly members of pardon over 6 weeks July and August 2013 and received 102 responses. It is clear those who responded are becoming aware of their needs, yet the majority has problems getting this support, and the overwhelming result is a need for more deaf awareness training, as shown by the evidence.

Our main concern is that there has been little recognition for the needs of those deaf and HOH people who use speech, hearing aids, CI's and English in the UK.

There is going to be a need for access to the NRCPD register for communication professionals who can support this group (Lipspeakers, STTR and Notetakers) to protect this group in the same way as BSL users are protected through the regulatory body.

NRCPD register (page 7- 8) shows that more than 90% of registered NRCPD professionals support BSL communication. For comparison, in the Netherlands, there are currently 87 registered speech to text reporters.*

In Holland there are 1.5 million registered deaf and hard of hearing people.***

Reference:

*Annex 3

**www.stichtingrtg.nl

***<http://www.hoorwijzer.nl/vraagbaak/veelgestelde-vragen/veelgestelde-vragen/hoorproblemen-in-nederland.html>

We are also concerned for the mental health issues of deaf people who use English as there is currently no support in this area and assumptions are made about needs of communication support.

There is lack of awareness of the different communication support in all public services including Police, NHS, Local Councils, Social Services, Job Centres with frontline staff lacking correct Deaf Awareness Training*

We welcome Sir Malcolm Bruce initiative to set up a body, which will look at the evidence, case studies and try to find a way forward to make sure all deaf people have equal access to society.

We support Prague Declaration 2013**as a benchmark for the work of the new body where needs of deaf, deafened and hard of hearing people are concerned and guiding principles of UN CRPD.

* Correct Deaf awareness training should cover ALL sectors of deafness, including needs of HOH people, Deafened people, BSL users and those who have either congenital or acquired age related deafblindness (ref: http://www.signature.org.uk/documents/deliver/qualification_specifications/DAC1_Qual_Spec_12-13.pdf)

** Annex 4

With thanks to the National Association for Deafened People for providing the communication support (STTR) during Parliamentary meeting with Sir Malcolm Bruce MP.

**This report is a joint project by the team of Pardon Group.
We have had no financial support and our time is entirely voluntary.**