RN Supporting people who are deaf, have hearing loss or tinnitus

How Westminster needs to transform the lives of people who are deaf, have hearing loss or tinnitus

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## RNID are here for the millions of people across the UK who are deaf, have hearing loss or tinnitus.

With our communities, we're changing society to make it more inclusive for everyone, help people hear better now and fund world-class research.

Our communities are huge: **one in five** adults in the UK are deaf, have hearing loss or tinnitus.

If our work doesn't directly impact you, it will almost certainly be making a difference for someone you know and love.

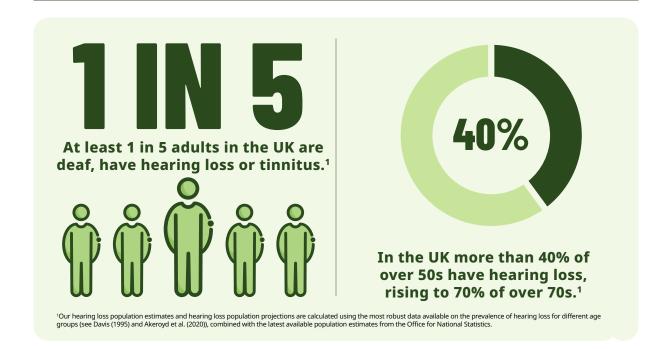
# **INTRODUCTION: CHANGING SOCIETY**

For a deaf person in a hearing world every day is a challenge. It could be the healthcare system not meeting your communication needs, an employment market which discriminates against you or lack of awareness of your communication needs in shops, services or social settings.

That's why RNID is changing society to make it more inclusive for everyone.

RNID worked with MPs from all parties across the 2019-2024 Parliament to improve the lives of people who are deaf, have hearing loss or tinnitus. RNID successfully collaborated with other deaf, disability charities and MPs to secure the BSL Act 2022, legislate for minimum levels of subtitles on on-demand TV, and drive improvement to Access to Work and other disability employment schemes. We secured vital commitments from Government to improve the accessibility of its own communications, defeated proposals to ration NHS hearing aids, improved the data collected on the life chances of BSL users, fought local restrictions to wax removal services and made many other contributions to improving public policy for our community.

#### But there is more we must do.





We have identified four key areas where progress must be made across the next Parliament.



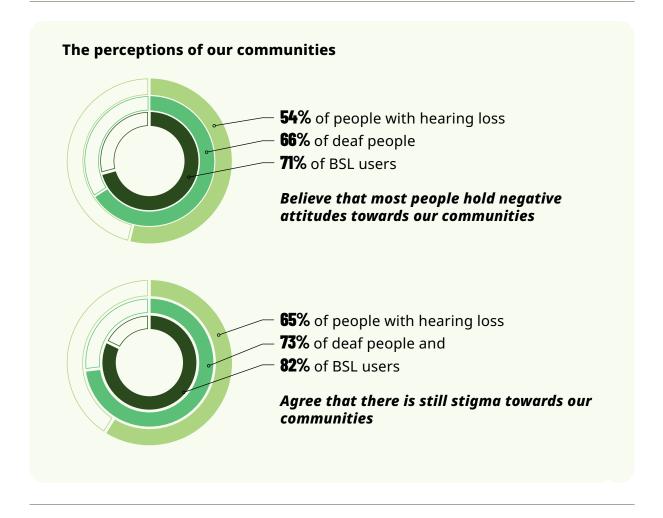
All of RNID's work is underpinned by what people tell us matters. We regularly carry out research to understand more about the life experience of deaf people and those who have hearing loss or tinnitus. This helps us to decide what issues we campaign on and then develop our policy positions in health and social care, employment, and beyond.

### RNID'S CAMPAIGN TO IMPROVE PUBLIC ATTITUDES TOWARDS DEAF PEOPLE AND PEOPLE WITH HEARING LOSS

**RNID: Loud and Clear** 

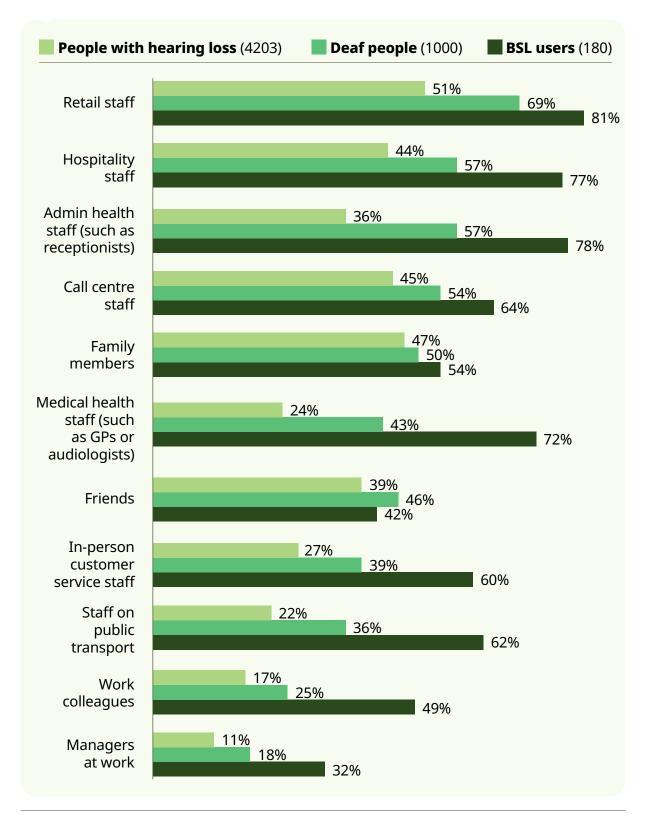
As part of RNID's commitment to making society more inclusive, this year we set out to understand the assumptions, challenges and misconceptions people with hearing loss and people who are deaf face on a daily basis when interacting with the general public and to determine what changes we need to see and make in the world.

By surveying 5,383 people who are deaf or have hearing loss and 2,768 members of the public, we found that our community share the common experience of having negative interactions with the general public across different areas of daily life.



We did this research to understand both public attitudes towards deaf people and people with hearing loss, as well as the lived experiences of our communities. We wanted to learn what assumptions, challenges and misconceptions people face on a day-to-day basis to help us understand what changes we need to see and make in the world.

It was clear that people faced negative attitudes across different areas of life- with particularly common negative interactions with retail staff, hospitality staff and admin health staff. We found that over two thirds (67%) of our communities say they have experienced negative attitudes or behaviours, and almost half (48%) have experienced this from their own family members.



Over half (54%) of our community report being told 'It doesn't matter...' by someone when they asked them to repeat something they missed. This phrase has a significant impact on our communities by making them feel different and excluded from conversations.



One participant with hearing loss said:

"One of the worst things is when people say something I miss and when asked to repeat they say 'oh it doesn't matter'. It probably didn't matter to them at the time, but it makes me feel **I DON'T MATTER.**"

Another common negative experience shared by our communities is being ignored, where, in particular, 59% of BSL users feel that most people ignore them in public settings. We also found that people also felt rushed, were not spoken directly to or were shouted at by members of the public when they had to interact with them.

The next Government will have to lead by example in tackling negative public attitudes by ensuring that they take into account the needs of our audiences in Government communications, and also considering these groups in the implementation of policy across different departments.



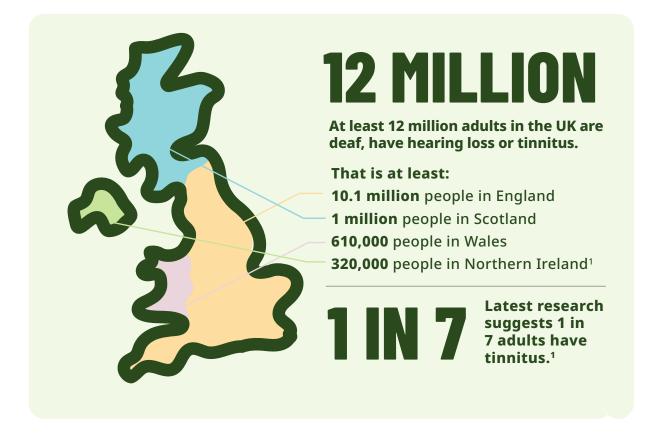
# MAKING CAMPAIGNING ACCESSIBLE

Given that one in five adults in the UK have hearing loss or tinnitus, all parties and candidates at this election will need to be deaf aware if they are to communicate effectively with the whole electorate.

Visit our website for advice and support

such as everyday communication tips, how to use the accessibility features on video calling platforms, and details on how to subtitle your content on various social media platforms.

For more information please see rnid.org.uk/accessible-election





#### WHAT YOU CAN DO

We want everyone to feel confident talking to deaf people and people with hearing loss. Here are a few simple tips from our communities:



### AND NEVER SAY: 'IT DOESN'T MATTER' ...

There's lots more you can do to help. Check out how you can get involved and learn more.



# OUR FOUR CALLS TO THE GOVERNMENT

**RNID: Loud and Clear** 

## **1. DELIVER CONSISTENT ACCESS TO HIGH QUALITY NHS AUDIOLOGY SERVICES**



#### **THE PROBLEM**

- In recent years, audiology services have faced significant simultaneous challenges due to staff shortages and inadequate funding to meet demand. These challenges have been compounded by COVID-19 service disruptions and competing national health priorities. Worryingly, services have not yet returned to pre-pandemic levels of activity, meaning more and more people are waiting for an audiology appointment.
- There is **no systematic process within the NHS to encourage people to check their hearing**. This goes against the strong evidence that untreated hearing loss is the largest potentially modifiable risk factor for dementia and is a substantive risk factor in other health conditions such as depression, falls and social isolation.
- NHS patients face a postcode lottery for wax removal services. Less than half of English ICBs provide wax removal services for all their patients, forcing those that can afford to, to pay £50-100 per ear for the service. This goes against National Institute of Health and Care Excellence (NICE) guidance, as excess ear wax can cause pain, discomfort and is often associated with wasteful referrals into expensive secondary care.<sup>2</sup>
- **Medical research into hearing loss is underfunded**, delaying the point at which people can benefit from treatments and cures.

#### WHAT NEEDS TO HAPPEN

The Government must take urgent action to ensure that people have access to high quality NHS Audiology services, including access to ear wax removal services and increased funding for biomedical research into new treatments.



# **1.2 MILLION**

An estimated 1.2 million adults in the UK have hearing loss severe enough that they would not be able to hear most conversational speech.<sup>1</sup>



Despite hearing aids being free and available on the NHS, an estimated 5 million people in the UK who could benefit from them do not have them.<sup>2</sup>



Hearing loss is estimated to cost the economy £30 billion a year due to lost earnings, reduced quality of life, additional GP visits and increased social care costs.<sup>4</sup>

#### **ONLINE HEARING CHECK**

RNID has a free online hearing check which enables anyone to check their hearing in just three minutes. Over 168,000 people completed it last year.

The online hearing check is for anyone aged 18 or over who has not been diagnosed with hearing loss. The check measures how well you can hear speech when there's background noise.

It tells people if they need to see a health professional about their hearing and get our advice on what to do next.





Recognise the importance of hearing loss as a wider determinant of health outcomes and introduce a national screening check to enable early identification and intervention.

Introducing a national screening check for hearing would enable earlier identification and intervention, meaning that people who could benefit from hearing aids would have access to them before they develop further complications. In the long term, this would reduce the burden on NHS resources.

The RNID Hearing Check demonstrates that a digital check could be embedded within either the existing NHS Health Check as that becomes a digital process, or included within the NHS App which will increasingly be used to proactively push screening checks to people. Ensure patients have access to NHS wax removal services, provided in primary or community care and in line with NICE Guidance.

Ear wax removal is a vital service for maintaining people's quality of life and wellbeing. Where people are unable to access timely NHS wax removal services, they can experience painful and distressing symptoms, be denied essential audiological care or diagnosis, or experience poor mental health.

In England, access to NHS wax removal services is a postcode lottery. Less than half of local commissioners are ensuring that this service is available to all adults where there is clinical need, in line with NICE guidelines.<sup>5</sup>



Transform the audiology pathway to ensure a high-quality service, tackling the short-term problems around waiting lists and creating a service fit for the future.

The current model of audiology is outdated and unfit to address the short-term challenges of waiting lists as well as the longer-term trend of increasing prevalence of hearing loss due to the UK's ageing population.

The audiology pathway is ripe for innovation. The use of technology to facilitate remote care and increase device uptake could provide immediate shortterm improvement, while there is potential for greater transformation of services for the long term which would help to ensure that the NHS is protected from greater pressure in the future.

#### What do patients want from future audiology services?

A RNID study found that people want to see different service models, improved accessibility and communication, and new technologies that support patient empowerment. 75% of respondents are interested in getting online support for problems with hearing devices; 48% would be interested in remote tuning and 34% would be interested in having all or most treatment done remotely.<sup>6</sup>

Service users want to see access to the latest technology and for a broader range of 'hearing' devices to be made available on the NHS, making full use of the technology that is now available.

#### **RNID NEAR YOU**

RNID partners with NHS audiology services in some parts of the UK to provide our hearing aid support service. This service supports people to get the most out of their NHS hearing aids. It helps people maintain their hearing aid – for example supporting people to change batteries or retube their device – as well as providing information on:



- how to look after and clean their hearing aids
- what to try if someone is having a problem with their hearing aids
- hearing loss and the assistive devices and technology that could help them
- other local services and organisations that can help.

RNID Near You benefits the NHS audiology service as well as the individuals themselves. The service also stops people having to go back into hospital for minor repairs, freeing up audiologists' time and creating a more efficient pathway.

The service is supported by a team of volunteers, many of whom are deaf or have hearing loss themselves.

#### Increase the funding in biomedical research for hearing loss and tinnitus, redressing a long-term underinvestment in the field.

There are currently no effective treatments and cures for hearing loss or tinnitus. Investment in research is vital for ensuring that new and better treatments are available to transform people's lives; however, hearing loss research is hugely underfunded. This gap must be closed.



**0.45%** Only 0.45% of public health research spend in 2022 supported ear research.<sup>7</sup>



Just £1 was spent on ear research for each person affected in 2022. This compares to £14 on eye research per person living with sight loss, £22 per person living with cardiovascular disease and £156 per person living with cancer.<sup>7</sup>



#### **THE PROBLEM**

Healthcare remains inaccessible for people who are deaf or have hearing loss.

- Two thirds (67%) of deaf people reported that no accessible method of contacting their GP has been made available to them.<sup>8</sup>
- 72% of deaf BSL users reported experiencing negative attitudes from medical staff such as GPs or Audiologists in the last year.<sup>15</sup>
- 4 in 5 (81%) of patients with communication needs reported having an appointment when their needs were unmet.<sup>8</sup>

#### WHAT NEEDS TO HAPPEN

The Government must ensure that access to healthcare for deaf people and people with hearing loss is delivered through enforcing the implementation of the Accessible Information Standard (AIS) and ensuring that all NHS staff are deaf aware and informed of their obligations under the AIS.

#### Realise the full potential of the Accessible Information Standard (AIS), including effective monitoring and enforcement of its implementation.

The AIS sets out clear guidance on what providers must do to make their services accessible to people with disabilities and sensory loss. It establishes a consistent approach to make sure people with disabilities and sensory loss fully understand the information they are give, and can participate in further discussions about their treatment and care.

The Health and Care Act 2022 increased the duty of NHS providers from one of having 'regard to an information standard' to stating they 'must comply with the information standard'. The legislation also contains an important provision which allows the Secretary of State to compel NHS providers to prove their compliance with the legislation.

The relevant provisions of the 2022 Health and Social Care Act have not, yet been enacted and brought into force. This needs to happen as quickly as possible and the Department of Health and Social Care should utilise those powers to compel publication of documents relating to compliance with the Accessible Information Standard.

#### Mandatory training on deaf awareness and the AIS for all NHS staff

The many stories about the poor treatment received by BSL users within the NHS indicate that there is an underlying ignorance of BSL and Deaf culture.

We want to see the NHS include a requirement for mandatory deaf awareness training for frontline NHS staff; empowering staff with skills to support BSL users, people who are deaf or have hearing loss. This would cover simple communication tips and the basic skills in communicating with all of our community. The 2022 Health and Care Act set an important precedent by requiring mandatory training on autism and learning disabilities and this should be replicated to ensure that patientfacing NHS staff receive meaningful deaf awareness training.

The total number of people in the UK who use British Sign language (not necessarily as their main language) is estimated to be 151,000 and, of these, 87,000 are deaf<sup>9</sup>



# **3. GUARANTEE EQUAL OPPORTUNITIES IN THE WORKPLACE**



#### **THE PROBLEM**

- People who are deaf and have hearing loss face barriers entering, remaining, and progressing in the workplace. Our community is less likely to be in employment than the non-disabled population.
- 49% of BSL users and 25% of deaf people report experiencing negative attitudes in the last 12 months. <sup>15</sup>
- Employers lack support and knowledge to assist people with hearing loss and people who are deaf in the workplace. There is little guidance and information to support employers around disability employment and signpost to the support that is available.
- Access to Work provides essential support for people who are deaf or have hearing loss, but the scheme is not widely known about, is blighted by poor and slow administration, and too often behaves as if it knows better than the individual claimant when it comes to what support will work for them.

#### WHAT NEEDS TO HAPPEN

Deaf people, people with hearing loss and tinnitus should be able to achieve, retain, and thrive in employment, on an equal basis to others. To deliver this, meaningful action must be taken to close the disability employment gap by helping employers meet their obligations and empowering our communities through reforming Access to Work.

## Set an ambitious dual target to close the disability employment gap.

For equality to be achieved, the Government must close the disability employment gap and set clear targets to measure progress. We have welcomed the existence of a Disability Employment Target since 2015 and believe that this helped galvanise government and incentivise parliamentary scrutiny of progress. It is positive that Government met its target to get an additional one million disabled people into work– but this was done without making a meaningful difference to the disability employment gap (the difference in employment rate between disabled and non-disabled people).

A new disability employment target must be set in the new Parliament.

The target needs to have a dual element: both increasing the number of disabled people in work, and closing the disability employment gap.



#### **INSIGHTS FROM RNID'S HEARING LOSS AT WORK REPORT**



In our 2022 survey, we found that 27% of employers did not feel knowledgeable about hearing loss and 76% did not feel confident communicating with someone who uses BSL. Additionally, 30% said they would not know where to get advice about employing someone with hearing loss.<sup>10</sup>

#### Help employers meet their obligations and replicate best practice through the creation of a Disability Information Hub and reform of the Disability Confident scheme.

To address gaps in employer knowledge and low-confidence in hiring disabled people, the Disability Confident Scheme needs to be reformed and sit alongside a central hub of information, resources and guidance for employers related to recruiting, retaining and supporting disabled employees. This would make a meaningful difference to employers and give them the confidence and knowledge to support their employees fully.

There is a need for a system that places greater expectations on employers alongside providing better support for individuals. The current programme lacks ambition, as well as robust auditing or assessment. The scheme should focus on the experience and outcomes of deaf and disabled people in the workplace, combined with insight from the DWP's Business Leaders Group.





#### Reform Access to Work to offer effective support for deaf and disabled people

Access to Work (AtW) provides vital financial support to deaf and disabled people in the workplace by helping employers meet the costs associated with hiring people with disabilities. However, deaf and disabled people face significant delays in accessing the support they need.

Access to Work customers need a quick and efficient service which issues awards within weeks, rather than months, of applications being made. Given the current backlog and delays (see box below), packages of support should be automatically extended until renewals can be processed and provisional awards for jobseekers should be introduced to make sure no claimants are left without support.

The programme should be marketed to employers and jobseekers so both groups know that financial support is available for when deaf people and people with hearing loss are employed. The Government must also co-produce a standard of service delivery for Access to Work which should be publicly available to help inform people what they are entitled to. Additionally, the remit of the programme should be extended to make it available for job seekers undertaking work-related activity or volunteering, as a means of preparing for work.



#### WAITING FOR ACCESS TO WORK

In 2023 there were over 20,000 applicants awaiting a decision every month and the average wait time from application to decision was still 40.8 working days (8 working weeks). This is a significantly long time to wait for someone who is starting a new position. The longest recorded wait time for an Access to Work decision in the last 12 months was 354 working days.<sup>11</sup>

# **4. WORK WITH THE BSL COMMUNITY TO TRANSFORM THEIR LIFE CHANCES**



In 2022, following a campaign from the Deaf Community, the British Government passed the British Sign Language Act 2022 (BSL Act), which recognised BSL as a language in its own right in law and required Government departments to report on how they are ensuring their communications are promoting or facilitating the use of BSL. However, this law has not delivered all the promises made to the deaf community.

#### **THE PROBLEM**

- There is a serious lack of evidence capturing the experiences and life outcomes of BSL users in the UK. There is not even a consensus on the total number of BSL users or Deaf BSL users in the UK.
- 82% of deaf BSL users agree that there is still stigma towards people with hearing loss and people who are deaf in the UK. <sup>15</sup>
- Deaf BSL users are excluded from participating in public life due to a lack of accessible Government communications.
- Deaf people are not properly involved in the public policy making process. Government needs to learn how to work with the Deaf community to engage in genuine co-production of the policies which impact their lives.

#### WHAT NEEDS TO HAPPEN

Government must work with the deaf community to make society more inclusive for deaf BSL users by improving the evidence base and processes through which policy decisions are made, and growing the meaningful inclusion of BSL users in public life.



difficulty hearing as 74.7%.<sup>12</sup> Only 37% of people who report BSL as their main language are working, in comparison to 82% of people who are not disabled under the Equality Act.<sup>13</sup>

Ensure that national and official surveys recognise the unique position of deaf BSL users who face greater barriers to accessing services and participating in society due to the language barrier that they face and measure them as a separate group.

Too often evidence on the life chances of Deaf BSL users is lost because of the way it is collected. For example, the Labour Force Survey (the largest survey on the UK's workforce) conflates BSL users with people with hearing loss in the category "difficulty hearing", preventing accurate measurement of how many BSL users are unemployed and are in need of further employment support.

This problem is replicated across Government datasets in health, education and all sorts of measures of life chances and must be rectified to support evidence-based policy making.



Government communications should be accessible for BSL users and RNID's accessible communications checklist should be embedded as best practice across Government.

As the Head of Government the Prime Minister has a particular moral obligation to ensure No.10 press conferences have a BSL interpreter in-view to ensure that deaf BSL users have access to moments of national importance.

The 2022 BSL Report showed that 11 departments reported that they produced no communications in BSL in the time-frame covered. Additionally, only six reported using BSL in press conferences, social media or Government websites to publicise activities or policies. The lack of resources produced by the Treasury during a cost-of-living crisis excluded BSL users from getting vital information about the support potentially available to them. The Department for Health and Social Care only had one consultation document translated into BSL.<sup>14</sup>

During the Covid 19 Pandemic, Westminster Covid Briefings were widely criticised by the deaf community for lacking an interpreter as it meant deaf BSL users lacked access to essential information about public health and safety.

During the pandemic we worked with disability charities to create an accessible communications checklist, setting out the basic steps that must be taken to ensure deaf and disabled people are reached with government messages, this should be adopted across government.

#### Retain the non-statutory BSL Advisory Board but evolve it to a model of genuine co-production on policies that impact the lives of the Deaf community.

To ensure that the BSL Act is implemented fully, the Government needs to continue to engage with the BSL Advisory board, which is made up of representatives from the deaf community.

The current remit of the board is focused on the implementation of the BSL Act and offering advice on the drafting of guidance under the BSL Act. We want Government to strengthen the remit of the Board so it can participate in genuine co-production and drafting of guidance which dictates how the government meets the needs of the Deaf community in areas such as healthcare, education and public service access.



#### REFERENCES

<sup>1</sup>Our hearing loss population estimates and hearing loss population projections are calculated using the most robust data available on the prevalence of hearing loss for different age groups combined with population estimates from the Office for National Statistics (ONS). For more information see: Akeroyd MA, Browning GG, Davis AC, Haggard MP. Hearing in Adults: A Digital Reprint of the Main Report From the MRC National Study of Hearing. Trends in Hearing. 2019;23. doi:10.1177/2331216519887614

<sup>2</sup>EuroTrak 2022 UK Survey data and adoption.

<sup>3</sup>NHS England Diagnostic Waiting Times and Activity Data https://www.england. nhs.uk/statistics/statistical-work-areas/ diagnostics-waiting-times-and-activity/ monthly-diagnostics-waiting-times-and-activity/; Stats Wales, Diagnostic and Therapy Services Data https://statswales.gov.wales/Catalogue/Health-and-SocialCare/NHS-Hospital-Waiting-Times/Diagnostic-and-Therapy-Services; Department for Health NI Diagnostic waiting times data https://www.health-ni.gov.uk/articles/ diagnosticwaiting-times. No data currently available for audiology waiting times in Scotland.

<sup>4</sup>Archbold, S., Lamb, B., O'Neill, C. and Atkins, J. (2014). The real cost of adult hearing loss. The Ear Foundation 2014.

<sup>5</sup>RNID, Blocked Ears Blocked Access: The crisis of NHS Ear Wax Removal in England, January 2024

<sup>6</sup>RNID, In Their Own Words: Insights and ideas from adult hearing service patients, February 2024

<sup>7</sup>2022 UK Health Research Analysis

<sup>8</sup>SignHealth and RNID, Review of the NHS Accessible Information Standard, February 2022 https://signhealth.org.uk/wp-content/uploads/2022/02/Review-of-the-NHS-Accessible-Information-Standard-FINAL.pdf

<sup>9</sup>BDA https://bda.org.uk/help-resources/#statistics There is no consensus on the total number of BSL users or deaf BSL users in the UK. There is enormous variation in the available estimates which makes it difficult to plan appropriate support and service provision.

<sup>10</sup>RNID, Hearing Loss at Work: Employer insights, January 2023

<sup>11</sup>The Minister for Disabled People listed the number of applicants awaiting a decision on their Access to Work Applications, (HC 21st February 2024, UIN 14096)

<sup>12</sup>Department for Work and Pensions, Official Statistics: Employment of Disabled People 2023, 26th October 2023 https://www.gov.uk/government/statistics/the-employment-of-disabled-people-2023/employment-of-disabled-people-2023

<sup>13</sup>2021 census

<sup>14</sup>Department for Work and Pensions, The British Sign Language (BSL) Report 2022, 31st July 2023

<sup>15</sup>RNID, It Does Matter: public attitudes towards deaf people and people with hearing loss, May 2024

We are RNID: the national charity supporting the 12 million people in the UK who are deaf, have hearing loss or tinnitus.

Together, we will end the discrimination faced by our communities, help people hear better now and fund worldclass research to restore hearing and silence tinnitus.

If you or someone close to you are deaf, or have hearing loss or tinnitus and need free confidential and impartial information and support, contact RNID. We are open 8:30am to 5.00pm, Monday to Friday.





**Call:** 0808 808 0123

Email: contact@rnid.org.uk



**Book a BSL video call via our partners at Sign Live:** create an account at the SignLive website or download the SignLive app for Android or the SignLive app for iOS

**SMS/text:** 07360 268988



Relay UK: 18001 then 0808 808 0123

Write: RNID, 126 Fairlie Road, Slough, Berkshire, SL1 4PY





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