

Northern Ireland

Why urgent action is needed on deafness, tinnitus and hearing loss across Northern Ireland

Hearing Matters

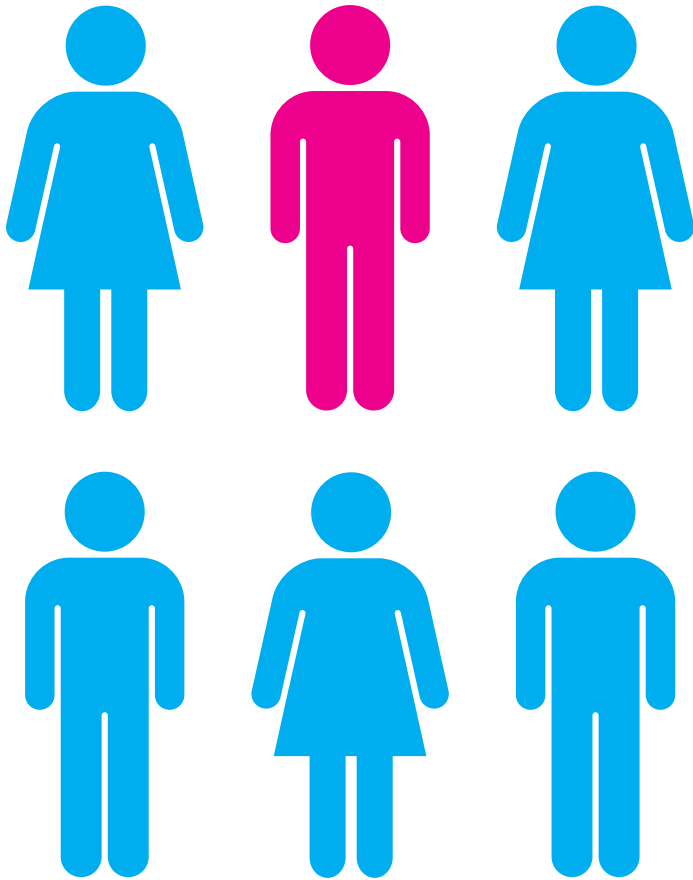


**ACTION ON
HEARING
LOSS**

NORTHERN IRELAND

A national charity since 1911





287,500
people have
hearing loss in
**Northern
Ireland**

That's one in six of us

Foreword

In this document we set out our priorities for the Northern Ireland Government. We also set out clearly the practical, cost-effective actions we want them to take to address these priorities.

Since the launch of *Hearing Matters* in 2011, considerable progress has been made towards improving the lives of people with deafness, tinnitus and hearing loss in Northern Ireland. Since 2011 we:

- have welcomed the Department of Health, Social Services and Public Safety (DHSSPS) Physical and Sensory Disability Strategy. The Strategy and associated Action Plan have resulted in considerable achievements. But, as it evolves through implementation and review, much work remains to be done
- welcomed the investment from the Northern Ireland Government in Hear to Help and specialist tinnitus services
- have published vital research on the needs of young people moving on from school
- have launched a clear plan to improve and standardise services for people with tinnitus
- have welcomed the Department for Employment and Learning (DEL) investment into the training of sign language interpreters.

All these developments are enormously positive. A number have already delivered positive outcomes and continue to do so, while others offer the promise of facilitating meaningful change in the future. But, much remains to be done to meet the needs of our community. Action on Hearing Loss Northern Ireland continues to be committed to working in collaboration with government and other partners, to support delivering the change that is required. We look forward to doing so, both now and in the years to come.

Jackie White, Director, Action on Hearing Loss Northern Ireland

Agenda for change

What action needs to be taken...

Support and care

Public health

- The Department of Health, Social Services and Public Safety (DHSSPS) should launch a second phase of the Physical and Sensory Disability strategy.
- It is essential to ensure that audiology-quality standards are enforced and better tinnitus services are developed.
- Additionally, we want to see greater cross-departmental, multi-agency working to improve access to education and employment. (please see pages 19-20 for training and employment actions).
- The DHSSPS should invest in a public health campaign to raise awareness of hearing loss.
- The UK's National Screening committee should introduce hearing screening for all people aged over 65 in Northern Ireland.

NHS Hearing services

- The DHSSPS should ensure that improvement and compliance against quality standards are routinely monitored and enforced, and publish the results.
- The Health and Social Care Board (HSCB) should commission and properly fund high-quality hearing services and make sure patients are able to access face-to-face follow-up appointments, and regular reassessments, after they've been fitted with hearing aids.

The Department of Health, Social Services and Public Safety should launch the second phase of the Physical and Sensory Disability Strategy

- Audiologists should provide better information on available services and increase referral rates to equipment and support services.
- The DHSSPS and the HSCB should work in partnership with voluntary-sector service providers across Northern Ireland, to improve the support available, as part of a comprehensive NHS aftercare service.

Tinnitus

- The DHSSPS should implement the tinnitus strategy for Northern Ireland as a matter of urgency.
- HSCB must commission consistently high-quality support services for people suffering with tinnitus.
- GPs and Health and Social Care Trusts should provide clear information about how to access tinnitus services.

Technology and treatments

- The DHSSPS should maintain the commitments it has made, through the Attributing the Costs of Research and Development guidelines, to support the indirect costs of charity-funded research in the NHS.
- The Department for Employment and Learning (DEL) should protect science budgets – and develop the research capacity of universities in Northern Ireland to attract more research funding.
- The Charity Research Support Fund should be increased in line with the increasing charity spend on research.

Equality

Access to communication support

- Urgent action is needed to increase the number of sign language interpreters in Northern Ireland by creating a sustainable training pathway.
- Sign language interpreting and audiology should be promoted as career opportunities.
- The Northern Ireland Assembly should ensure cross-departmental and multi-agency participation in the Department for Work and Pensions (DWP) review, to ensure that capacity and demand for sign language interpreters in Northern Ireland is properly evidenced and that any identified gaps in service provision can be addressed.

Access to health

- The DHSSPS must put in place, and enforce, mandatory standards to ensure all health and social care services are accessible. This should include a system for monitoring levels of accessibility of GPs and other health and social care services.

Transitions from education to employment

- The DEL, Department of Education and the DHSSPS should work together to ensure that services are providing tailored, ambitious and positive support to young people with hearing loss – equipping them with the knowledge, skills and confidence to enable them to make informed decisions which will affect the rest of their lives.

Access to employment

- The DEL must actively promote the Access to Work scheme to people with hearing loss and employers.
- Access to Work should be extended to provide support for people with hearing loss who are on work placements or voluntary placements as a route to work.

Support and care

Public health

GPs fail to refer

45%

of those reporting hearing loss to NHS hearing services

287,500 people in Northern Ireland have hearing loss and this number is set to grow as the population ages¹. It is estimated that 71.1% of over-70s have some form of hearing loss (Davis, 1995). About one in 10 people in Northern Ireland are also affected by tinnitus (Davis, 1989).

If untreated, hearing loss affects the ability of people to communicate with others and can lead to social isolation (Gopinath et al, 2012; Pronk et al, 2011) and depression (Saito et al, 2010). There is also strong evidence of a link between hearing loss and dementia (Lin et al, 2011). Evidence suggests that the timely provision of hearing aids can reduce these risks and improve quality of life (Mulrow et al, 1990; Deal et al, 2015), but people wait on average 10 years before seeking help and GPs fail to refer up to 45% of people to NHS hearing services (Davis et al, 2007).

In 2012, the Department of Health, Social Services and Public Safety (DHSSPS) launched the Physical and Sensory Disability Strategy and Action Plan (DHSSPS, 2012). The strategy committed the DHSSPS to improving the quality and accessibility of health and social care services for people with a physical disability or sensory impairment in Northern Ireland.

¹ The estimates of prevalence of hearing loss in this section are based on the most robust and best available data for prevalence at each age group (Davis, 1995), updated with Office of National Statistics population estimates for 2014 (ONS, 2015), and rounded to the nearest 500.

We are calling on the DHSSPS to launch a second phase of the Physical and Sensory Disability strategy, to address outstanding areas, including the need to take urgent action to enforce audiology-quality standards, develop high-quality tinnitus services, and urge professionals to improve access to education and employment.

What action needs to be taken...

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- It is essential to ensure that audiology-quality standards are enforced and better tinnitus services developed.
- Additionally, we want to see greater cross-departmental, multi-agency working to improve access to education and employment. (Please see pages 19-20 for Training and Employment Actions).
- The DHSSPS should invest in a public health campaign to raise awareness of hearing loss.
- The UK's National Screening committee should introduce hearing screening for all people aged over 65 in Northern Ireland.



Following my hearing test and hearing aid fitting, I was given an instructions booklet and told to come back if I thought I'd be better with two aids. No advice was given on how I should look after my aid. When I went to the Hear to Help drop-in to volunteer, I realised that my hearing aid wasn't fitted properly. I left with a much better idea of how to look after my aid - and I'm more confident wearing it. The audiologist was very pleasant, but I wish she'd told me that hearing aid tubing should be replaced regularly, or recommended Hear to Help.

Glenda Dixon, 61,
Annalong, County Down

NHS Hearing services

Quality standards for adult audiology services were introduced in Northern Ireland in 2013. Audiology services must be given the necessary resources to be able to meet their obligations under these standards. It is also crucial that their progress is monitored and reported on.

After being fitted with hearing aids, 66% of respondents to a survey in 2009 reported that they had some degree of difficulty using their hearing aids (RNID Cymru, 2009). Audiology services in Northern Ireland must get better at supporting people after they are fitted with hearing aids – our recent research (Lowe, 2015) shows that no audiology service in Northern Ireland offers automatic reassessment of patients' needs, compared to approximately a third (31%) across the UK.

It is also vital that information, emotional support and practical guidance are made available to people with hearing loss and their families as soon as possible after diagnosis and treatment. A survey of patients' experiences of audiology in Northern Ireland, carried out in 2014 (Action on Hearing Loss Northern Ireland, 2014a), found that the majority of patients did not receive information on assistive equipment and most were not signposted to other sources of support such as social services, voluntary-sector services or lipreading classes.


Our staff and volunteers have been providing aftercare services to people struggling to use their hearing aids since 2007, via outreach, at-home and drop-in services. Our Hear to Help services provide basic hearing aid maintenance such as re-tubing, ear-mould cleaning and battery replacement, as well as signposting people to support groups and social services.

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A recent evaluation showed that for every £1 spent on our Hear to Help service, £10.34 of extra benefits are created – in terms of reduced impact on the NHS, increased health and wellbeing, improved confidence and reduced isolation for people who benefit from the service, and benefits to volunteers (Boyle, 2014).

What action needs to be taken...

- The DHSSPS must ensure that improvement and compliance against quality standards are routinely monitored and enforced, and publish the results.
- The Health and Social Care Board (HSCB) must commission and properly fund high-quality hearing services and make sure patients are able to access face-to-face follow-up appointments, and regular reassessments, after they've been fitted with hearing aids.
- Audiologists should provide better information on services available and increase referral rates to equipment and support services.
- The DHSSPS and the HSCB should work in partnership with voluntary-sector service providers across Northern Ireland, to improve the support available, as part of a comprehensive NHS aftercare service.



I was sent to an ENT Consultant who said, “You’re the fifth person I’ve seen today. Go away and learn to live with it.” This ‘invader’, as I christened my tinnitus, followed me everywhere and became a thief of concentration. I’d been about to study for my PhD but that was a no go. I felt so angry about the huge impact tinnitus was having on my personal life.

Christine Martin, 69, Belfast

Tinnitus

Around one in 10 people in Northern Ireland are affected by tinnitus (Davis, 1989), which is a ringing or buzzing sound in the ear or head that cannot be attributed to an external source. Most cases are related to ageing, hearing loss or noise exposure. It can also be a side effect of ear or head injuries, ear disease or infections and can be triggered or exacerbated by emotional trauma, illness or stress. Evidence suggests that tinnitus is linked to depression, which can worsen the perception of the condition (Dobie, 2003).

GPs are not always equipped with the appropriate knowledge and information to help people with tinnitus and there is no clear pathway for people with tinnitus to get help. Action on Hearing Loss research (2015) showed that services are inconsistent across Northern Ireland.

The Health and Social Care Board (HSCB) in Northern Ireland currently funds Action on Hearing Loss Northern Ireland to deliver a specialist tinnitus service in partnership with local Health and Social Care Trusts. Delivered by tinnitus specialists, this service provides a range of support and advice for people with tinnitus. This service should continue to be provided through HSCB procurement, so that people living with tinnitus in Northern Ireland can have access to the support they need.

In 2013 we produced a comprehensive tinnitus strategy for Northern Ireland (Action on Hearing Loss Northern Ireland, 2013), in collaboration with experts from across health, social services, and the voluntary sector. It called on every Health and Social Care Trust

to provide specialist tinnitus services in their area and improve the quality of tinnitus information available for patients and their families. It has yet to be implemented by the DHSSPS.

There is no clear pathway for people with tinnitus to get help

What action needs to be taken...

- The DHSSPS should implement the tinnitus strategy for Northern Ireland as a matter of urgency.
- The HSCB must commission consistently high-quality support services for people suffering with tinnitus.
- GPs and Health and Social Care Trusts should provide clear information about how to access tinnitus services.

Technology and treatments



We should establish Northern Ireland as an international leader in hearing loss research

Evidence shows that, per head of population, Northern Ireland attracts a smaller amount of research funding from charities and research councils than Scotland or England.

Despite the lack of funding, crucial research is being undertaken. For example, Dr Trevor Agus from the School of Creative Arts at Queen's University, Belfast, uses psychoacoustic and neural-imaging techniques, such as Functional Magnetic Resonance Imaging, to study how we recognise different sounds. Dr Agus's team's research could improve the design of hearing aids – providing significant benefits for many people.

The expertise should be used to attract further investment and establish Northern Ireland as an international leader in hearing loss research.

What action needs to be taken...

- The DHSSPS should maintain the commitments it has made, through the AcoRD guidelines, to support the indirect costs of charity-funded research in the NHS.
- The Department for Employment and Learning (DEL) should protect science budgets – and develop the research capacity of universities in Northern Ireland to attract more funding.
- The Charity Research Support Fund should be increased in line with the increasing charity spend on research.

Equality

The rights of people with hearing loss in Northern Ireland are protected by the Disability Discrimination Act (DDA) 2005. The DDA bans discrimination and requires employers and service providers to make 'reasonable adjustments' to ensure disabled people can access goods, services and employment. Employers and service providers must make sure their policies and practices do not discriminate against people with hearing loss. For example, people with hearing loss may not be able to use the telephone and services should offer alternative contact methods such as email or video-relay services. Employers must also take steps to ensure recruitment and selection processes are accessible for people with hearing loss.

Access to communication support

Many people living with deafness and hearing loss need communication support, including access to sign language interpreters.

In 2008 the DEL committed £1.3m to increase the number of sign language interpreters and tutors in Northern Ireland. A new qualification was created to enable interpreting students to achieve a Masters-level qualification in sign language interpretation. A one-year progression course was piloted at Belfast Metropolitan College to 'feed' students on to Queen's University to complete an MA in Translation.

But the training of sign language tutors has been delayed, so right now there are no teachers of Level 3 sign language or above in Northern Ireland. Student interpreters are left with no choice but to study outside the region, at their own expense, for at least part of their progression to qualified status.

The UK Government's Department for Work and Pensions (DWP) is leading on a review of the language and communication support market for people who are deaf or have hearing loss (House of Commons Written Statement, 12 March 2015). The review, due to report early in 2016, will look at provision in the UK as a whole and will include all forms of language and communication support, including sign language interpreters.

Many GPs are still unaware of the needs of people with hearing loss

What action needs to be taken...

- Urgent action is needed to increase the number of sign language interpreters in Northern Ireland by creating a sustainable training pathway.
- Sign language interpreting should be actively promoted as a career opportunity.
- The Northern Ireland Assembly should ensure cross departmental and multi-agency participation in the DWP review, to ensure that capacity and demand for sign language interpreters in Northern Ireland is properly evidenced and that any identified gaps in service provision can be addressed.

Access to health

Our research (RNID Northern Ireland et al, 2009) showed that less than half (47%) of GP practices in Northern Ireland made reasonable adjustments specifically for people with a sensory disability, despite the legal requirements of the DDA.

The findings revealed that GPs were unaware of the needs of people with hearing loss. GP-surgery staff training was inadequate, hearing loops were only available in approximately a fifth (18%) of consultation rooms, and less than half (46%) of GP surgeries could be contacted by email to book appointments.

The HSCB has developed guidance for GPs on improving access to their services for people with sensory loss. But, to be effective, the guidance must be properly implemented and enforced.

What action needs to be taken...

- The DHSSPS must put in place, and enforce, mandatory standards to ensure all health and social care services are accessible. This should include a system for monitoring levels of accessibility of GPs and other health and social care services.

Transitions from education to employment

For young people with hearing loss, transitions, such as the move from school to university or college, training or employment can be more complex than for people with normal hearing. This is because of a range of communication, attitudinal and institutional barriers.

Our research (Action on Hearing Loss Northern Ireland, 2014) shows that, throughout their education, there is a lack of careers planning for young people with hearing loss. Young people with hearing loss struggle to find information on additional classes after school, or support available in further or higher education. School leavers and university graduates also find it difficult to access careers advice after finishing school or university – the provision of qualified sign language interpreters is often inadequate and many school-teachers, Disability Advisers and Learning Support Officers are unaware of the communication needs of young people with hearing loss.

Young people with hearing loss tell us that careers guidance often seeks to lower their horizons and make them more 'realistic' about what they can achieve. In many cases, young people with hearing loss have been advised to pursue vocational, rather than professional careers; the implication being that hearing loss is a barrier to future career development. Young people with hearing loss are sometimes unaware of their right to request adjustments in the workplace and during job interviews.

What action needs to be taken...

- The DEL, Department of Education and the DHSSPS should work together to ensure that services are providing tailored, ambitious and positive support to young people with hearing loss – equipping them with the knowledge, skills and confidence to enable them to make informed decisions which will affect the rest of their lives.
- A programme of preparation for leaving school should be developed, to include: information on the full range of post-16 options; signposting to support and entitlements; confidence-building and life skills; work experience and taster days/visits; and talks from deaf role models.
- Information on transitions should be made available in different formats, including online, written text and video translation in sign language.



Employer attitudes and barriers to access are preventing people with hearing loss from finding and keeping jobs

Access to employment

The DEL's Access to Work programme makes a significant contribution towards communication support costs for people with hearing loss at work. But employer attitudes and barriers to access are preventing people with hearing loss from finding and keeping jobs.

The Access to Work programme is not available for people on work placements, volunteers, or for freelancers working less than eight hours a week. Without access to communication support for temporary work, many people with hearing loss are unable to gain work experience, find work or progress in their careers.

What action needs to be taken...

- The DEL must actively promote the Access to Work scheme to people with hearing loss and employers.
- Access to Work should be extended to provide support for people with hearing loss who are on work placements or voluntary placements as a route to work.



As a nurse teacher, Access to Work has helped me in many ways. For instance, with listening devices and other equipment to aid me. I feel Access to Work has actually helped my deafness be properly acknowledged by my employer/manager, and I believe the organisation has learned something in the process. This support has been invaluable; allowing me an extra few years in nursing practice.

Amber Huey, 60, Derry/Londonderry

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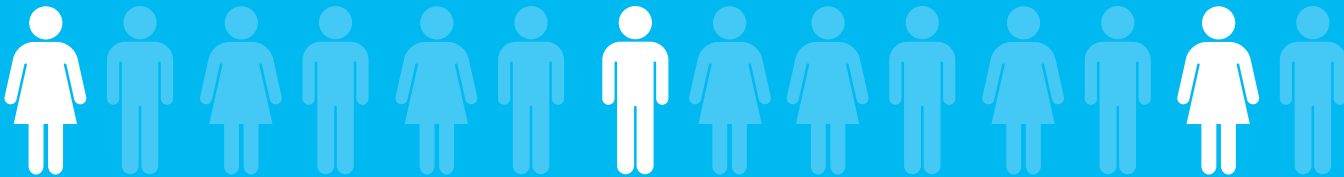
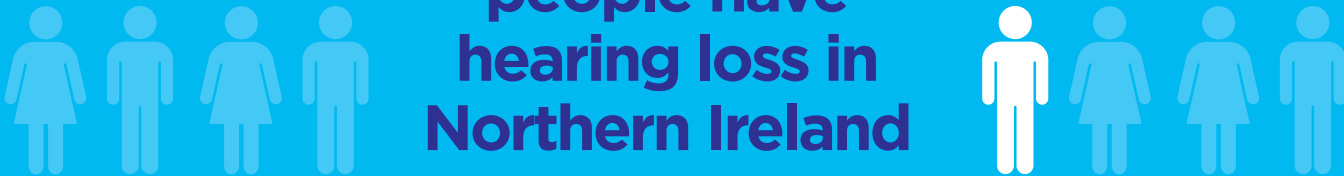
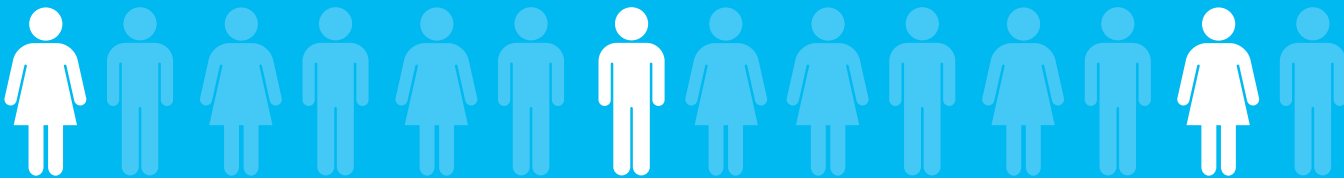
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Our purpose is to help people confronting deafness, tinnitus and hearing loss to live the life they choose. We enable them to take control of their lives and remove the barriers in their way.

To find out more about what we do and how you can support us, go to www.actiononhearingloss.org.uk/northernireland

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On the cover: Glenda from Annalong, County Down.
Glenda shares her story on page 9.



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