

Working together to create an equal world for people who are deaf, deafblind, have a hearing loss or tinnitus

A policy manifesto for the Northern Ireland Executive

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Background

The Coalition on Deafness brings together key charitable organisations in Northern Ireland that are working to improve the lives of people who are deaf, deafblind, have a hearing loss or tinnitus.

It is agreed within our sector that the issue of hearing loss and deafness has not been adequately addressed by Government, in spite of improvements in legal protection and increasing obligations on public bodies to meet the needs of people with disabilities. The numbers of people with hearing loss in Northern Ireland far outweigh any other category of disability and yet significant numbers of people continue to face discrimination, barriers to social inclusion, are denied equality of opportunity and endure daily challenges in accessing services which everyone else takes for granted.

The Coalition believes that by working in partnership we can create truly transformational change for our client group, as has been realised by other disability groups in recent years.

Through the publication of this Manifesto, we hope to

- Promote the rights of deaf, deafblind and hard of hearing people
- Raise awareness of the exclusion faced by deaf, deaf-blind and hard of hearing people as a result of the barriers they encounter.
- Recommend actions to address those barriers.

Hearing loss is a major public health issue in Northern Ireland, with almost 300,000 people affected by some form of hearing loss – that's one in six¹ of the population. As our society ages, the numbers are set to grow – 42% of people aged over 50 have some form of hearing loss². There are 20,000³ people in Northern Ireland who are severely or profoundly deaf. In addition, tinnitus severely impacts on the quality of life of at least 7000 people⁴.

¹ Action on Hearing Loss 2013

² Action on Hearing Loss 2013

³ Action on Hearing Loss 2013

⁴ 'What's That Noise', Action on Hearing Loss NI 2011

There are thousands of people with unaddressed hearing loss - of the 300,000 people in Northern Ireland with hearing loss, up to 115,000⁵ could benefit from hearing aids.

There are more than 1,400 children⁶ with hearing loss in Northern Ireland, with over 260⁷ either profoundly or severely deaf.

Estimates indicate that the incidence of deafblindness is 572 per 100,000 of the population⁸. Based on the 2012 NISRA statistics this equates to 10,431 deafblind people in Northern Ireland.

Deafblindness impacts on communication, mobility and access to information, and deafblind people experience an increased risk of a range of health conditions including stroke, arthritis, heart disease, hypertension, falls and depression.

Hearing loss has significant personal and social costs and can lead to high levels of social isolation and consequent mental ill health. Up to 40% of people with hearing loss experience mental health problems at some point – nearly double the 25% in the general population.⁹

Hearing loss has serious economic ramifications, especially when people face barriers in getting a job or when it compounds other health problems.

Many people do not have equal access to employment, education, healthcare and other services.

Quick numbers guide:

Northern Ireland	
Total population with hearing loss	300,000
Children with hearing loss	1,400
Deafblind people	10,431
People with severe tinnitus in	7000
People who could benefit from a hearing aid	150,000

⁵ Action on Hearing Loss

^{6.&}amp;7 CRIDE report 2012, NDCS <u>http://www.ndcs.org.uk/professional_support/national_data/uk_education_.html</u> 8. Sense

^{9.} Paddock et al, 2008

Coalition Membership

At the time of this publication, the member organisations of the Coalition on Deafness are:

Action Deaf Youth (formerly NIDYA) Action on Hearing Loss Deafblind NI Hearing Link National Deaf Children's Society Northern Ireland Deaf Sports Sense Signature

We would like to acknowledge the contribution of The Association of Sign Language Interpreters (ASLI) to the section on 'Communication Support'.

The Manifesto

This manifesto presents a number of issues that the Coalition membership collectively agree have a substantial impact on the lives of deaf, deafblind and hard of hearing people in Northern Ireland.

This is the first time that all of the issues the membership organisations actively campaign on, or provide services to meet the needs identified, have been published in one document.

The manifesto uses a rights-based approach to consider these issues in the context of government responsibilities, analysing current policy and practice, and suggesting where change can produce positive outcomes for deaf, deafblind and hard of hearing people in Northern Ireland.

The aim of this document is to provide a guide to Government departments across the Northern Ireland Executive on the issues that they need to take action on, either individually or collectively.

The Coalition on Deafness will seek to work in partnership with Government to address these issues and to represent and enable the views of deaf, deafblind and hard of hearing people.

Structure of the Manifesto

This manifesto sets out the key issues under a series of themes. The context for each issue is outlined, supported by a case study, and the relevant human rights instrument is applied. Each issue is followed by a clear ask for Government departments and policy makers to address.

The Social Model of Disability

This manifesto is based on the 'social model' of disability and on the definition of disability contained in Article 1 of the UNCRPD. The Article 1 definition states:

"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others."

Crucially, the definition extends beyond an *individual's* impairment and requires that the needs of the deaf person are assessed in relation to the barriers that *society* erects that hinder their progress.

The Centre on Human Rights for Disabled People states,

'The medical model of disability views disability as synonymous with an individual's impairment and not as a consequence of the society in which we live. People with disabilities have rejected this model....They say it has led to their low self-esteem, undeveloped life skills, poor education and consequent high unemployment levels. People with disabilities have arrived at a different model to help understand the situation. This approach, known as the social model of disability...argues that disability is an issue of exclusion from everyday life....(it) locates the problem within wider society, and focuses on the characteristics and barriers presented by this disabling society. Such barriers include inaccessible buildings, unequal access to services a lack of information in alternative formats, prejudicial attitudes, or a lack of opportunities for people with disabilities to become involved in service planning and delivery. The implications of this approach are far reaching since the solution shifts from finding a cure to eradicating the disabling barriers constructed by society.¹⁰

The Coalition on Deafness has attempted here to identify the barriers constructed by society that negatively impact upon the lives of people who are deaf, deafblind, have a hearing loss or tinnitus.

¹⁰ 'We Have Rights Too' Developing a Disability and Human Rights Approach to Health and Social Care: A Toolkit. Centre for Human Rights for Disabled People, Disability Action, 2007

Human Rights Instruments and deafness

We have sought to refer throughout this manifesto to Human Rights instruments and International Standards. There are two Conventions in particular which have direct effect on the barriers faced by people who are deaf, deafblind, have a hearing loss or tinnitus - the UN Convention on the Rights of Persons with Disabilities, and the UN Convention on the Rights of the Child.

UN Convention on the Rights of Persons with Disabilities (UNUNCRPD)11

Adopted by the General Assembly in December 2006, the Convention was signed by the UK government in March 2007 and ratified on the 8th June 2009. The UK government did, however, note a reservation about the operation of Article 24 in relation to the state's responsibility to provide inclusive education only in mainstream provisions.

The UUNCRPD brings together, for the first time, the civil, political, social, economic and cultural rights of people with disabilities. It includes detailed rights across a wide range of services that impact on the lives of deaf and hard of hearing people, and includes rights that define reasonable adjustments to services for people with specific disabilities.

Rights that are specific to the needs of people who are deaf, deafblind, have a hearing loss or tinnitus include rights to access services using sign language, to access to Braille and other assistive technologies and to the promotion of the culture of the Deaf community.

UN Convention on the Rights of the Child (UNCRC)12

The UNCRC was adopted by the General Assembly in 1989. The UK government signed the Convention in 19 April 1990, ratified it on the 16 December 1991 and it came into force on the 15th January 1992. It gives children over 40 substantive rights.

¹¹ <u>http://www2.ohchr.org/english/law/disabilities-convention.htm</u>

^{12 (} http://www2.ohchr.org/english/law/crc.htm)

Overarching themes

Relevant rights

Article 3: General principles

Article 4: General obligations

Article 7: Children with disabilities

Article 8: Awareness-raising

Article 31: Statistics and data collection

Acceptance and attitude

Article 3 of the UNUNCRPD outlines as a general principle 'Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.'

However, we continue to live in a world where deaf people are disadvantaged and discriminated against, even in a modern society such as Northern Ireland.

Despite improvements in legal protection, such as equality legislation and the Disability Discrimination Act, people with hearing loss continue to face barriers to health and social care services, education, employment, transport, media and commercial services.

Those barriers can be *physical* - such as the use of intercom systems and automated telephony; *procedural* - such as having no process in place to provide communication support if required; and *attitudinal* - where individuals or organisations display negative attitudes to people with hearing loss in both subtle and overt ways.

There remains a fundamental problem in how deaf people and people with hearing loss are perceived. Hearing loss is often associated with ageing and a perceived reduction in function which has implications in terms of usefulness in society.

Stigma around hearing loss and deafness is demonstrated by not only the public at large but by people with hearing loss themselves, who often do not address their hearing loss until many years after decline in hearing has begun.

Hearing loss and deafness are still parodied in popular culture, and the issue has not benefitted from the change in attitude and behaviours which has made mockery of other disabilities taboo.

The aim of increasing acceptance of hearing loss as a common everyday matter, which should be taken into account in the delivery of services and in the behaviours of society, not as an additional consideration, but as a matter of course, is challenging.

Deaf awareness is a key issue. People are often not aware of the simple actions they can take to improve communication with someone who has hearing loss. Compared with other disabilities, hearing loss is the condition most likely to cause people concern about communication.

A recent public opinion poll¹³ found that more than one in three people (35%) are put off interacting with someone who is deaf or has a hearing loss, with 'I wouldn't know how to communicate with them' given as the main reason.

By raising awareness of the needs of people with hearing loss, deafness, deafblindness and tinnitus, by tackling stigma, and by encouraging everyone to place value on their hearing, attitudes can be changed.

Inclusion and participation

Article 3 of the UNUNCRPD outlines as a general principle 'Full and effective participation and inclusion in society', and further outlines in Article 4 that Government 'shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations, when designing policies and making decisions.'

However, in order to ensure that people who are deaf, deafblind, have a hearing loss or tinnitus are fully included in making decisions on issues affecting them, Government bodies must enable their participation.

This includes setting aside a realistic budget for communication support to enable service users to communicate effectively in meetings; providing information in alternative formats, such as in British Sign Language; providing training and support to individuals on how to participate

¹³ (nfpSynergy, 2010).

effectively; and training and supporting staff to enable them to engage effectively with people with hearing loss.

Organisations also need to measure the effectiveness of their inclusion and participation activities, and devise ways of reaching out to individuals who are not necessarily aligned to representative organisations, or who are deemed 'hard to reach'.

True inclusion and participation goes much further than consultation. A human rights approach to involving people who are deaf or have a hearing loss in decision-making and policy design, ensures that people are supported to become members of the design or decision-making panel, to steer the direction of the policy or service development, to advise on outcomes and interpret meaning, and to guide the promotion of the policy or service to others.

Universal Design

'Universal design' means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design. Universal design shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

The UNCRPD Article 4, Clause (f) requires that all Government Departments and Agencies consider the needs of people with disabilities when they are designing premises, preparing publications, but also when they are designing administrative processes and developing policy.

This is an important right for deaf children and adults. All too often in the past, services such as GP practices, paying for motor tax, educational testing or announcements on public transport have been designed with the assumption that everyone using the services can hear. The UUNCRPD says that this has to change.

The clause requires that departments and agencies agree

'To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines'. When planning new developments or writing policy, the needs of deaf people have to be considered from the outset and their needs 'designed into' the service, rather than being seen as an awkward add on after the rest of society's needs are met.

Partnership working

Charitable and voluntary organisations working with people with deafness and hearing loss have established a huge bank of knowledge, resource and expertise in identifying need and responding successfully to meet that need.

Effective partnerships should take account of the strengths of different players. For Government, valuing the knowledge and expertise of the voluntary and community sector and involving organisations at a different stage in service and programme development, can lead to more workable and high quality solutions.

For voluntary and community organisations, advocacy, which includes the identification of workable solutions and a willingness to engage in shaping and delivering the Government's aims, can help an organisation achieve its mission without compromising its independence.¹⁴

Government departments and service providers should also work in partnership with service users in the design of services at the outset.

Service users with hearing loss should be facilitated to participate in decision-making, equipped with the necessary skills and provided with the appropriate communication support to enable them to participate fully.

Case study

A common experience for deaf people when shopping is that the display screen of the shop till is facing away from them so they have no information as to the amount of money required to pay for the goods. Or, if the display screen is visible the amount displayed is that of the last item scanned, not the subtotal of the entire transaction. Deaf customers often report that they simply hand over a sum of money in the hope that it is enough.

¹⁴ The Rt Hon, Paul Boateng, MP and Fiona MacTaggart, MP. Adding Value to Public Services, RNID, 2004,

Frontline staff are often not deaf aware and therefore raise their voice in an attempt to be heard by a deaf customer. This can prove frightening for a profoundly deaf person as they are unable to hear what the service provider is saying and are looking at a contorted / angry face as a result of the person physically raising their voice. The service provider therefore appears angry with the deaf customer.

"Personally, I find that if the loop system is not available and I am not able to hear clearly, I feel like a second class citizen. When working loop systems are available, my wife relaxes because she knows I can hear, and enjoy what is happening, and we can discuss what we went to see because I haven't missed half of what is being said!"

Relevant rights

Article 31 - Statistics and data collection

Data collection

A rights-based approach involves effective monitoring and accountability. This should include collection of disaggregated data so that the way people with hearing loss are able to enjoy, exercise and claim their human rights across services can be effectively monitored. Accountability processes should be transparent and fully accessible.

Currently there is no official record of the total number of people with hearing loss, deafness, tinnitus or deafblindness in Northern Ireland.

Organisations working in this field rely on statistical extrapolations to provide approximate figures. The numbers of people registered with Social Services, through Education and Library Board services, GP practices, Job Centres, and recorded by the Census, do not give an accurate, or joined up account of the size or complexity of need, which services aim to address.

Case study:

The SOSCARE (Social Services Client Administration and Retrieval Environment) system that Health and Social Care Trusts use to record service user information does not allow for the accurate recording of service users with tinnitus. As a result, identifying evidence of need becomes problematic.¹⁵

Planning services for deaf and deafblind children

The New Born Hearing Screening Programme ensures that most deaf and deafblind children are known to statutory services from days after they are born. Yet there often remains a problem for education and health services in planning services to meet their needs. There is no coordinated collection of data about the existence of deaf and deafblind children, and no

¹⁵ 'What's That Noise' Personal and Professional Experiences of Tinnitus in NI, RNID 2010

coordinated outcome-based planning of services to meet their needs as they move through school, through transition services and into adult life.

Planning for the needs of deaf and deafblind children should include planning for the employment and training of staff to resource those needs.

In addition to their formal responsibilities under the Articles of the UNCRPD, education authorities also have an anticipatory duty arising out of wider human rights law to plan to meet such needs.

Case studies

More parents are opting to use sign language to raise their children, but find it difficult to have sign support written into Statements because of the lack of teaching assistants and communication workers with the appropriate skills.

Planning based on outcomes would lead to a more stable supply of qualified Teachers of the Deaf.

Coordinating services for deaf children

Many deaf and deafblind children require coordinated support services from a range of statutory and other providers. Only those children with Statements of Special Educational Need have an enforceable right to the services so provided, and that responsibility lies with the Education Authority, rather than other providers such as Health and Social Care.

Currently, there is no statutory responsibility on the part of statutory services to coordinate services for deaf and deafblind children.

Case studies

Many deaf and deafblind children will require services in addition to education, for instance, the need for speech and language support or physiotherapy.

There are many examples of deaf children missing out on such specialist services due to changes in services or recruitment difficulties, yet the impact on the child can often be substantial, particularly where it concerns the child's ability to communicate with parents, teachers or peers.

Coordinating services for adults with hearing loss

The 2011 Regulation and Quality Improvement Authority (RQIA) review of the impact of the Quality Standards for Social Work and Rehabilitation in Sensory Support Services (2007) made a number of recommendations for the Department of Health, Social Services and Public Safety and the Health and Social Care Board and Trusts.

This included the need to revise the Standards in light of emerging developments, the need for a standardised register across Northern Ireland for persons with sensory support needs to aid the commissioning process, and a number of more detailed recommendations around access to information, reablement and communication support.

The Regional Sensory Impairment Group, made up of statutory and voluntary sector service planners and providers, is taking forward these recommendations, and in particular to 'further develop the Care Pathway for sensory services to incorporate Community and Voluntary Organisations, Health Promotion and Prevention of Sensory Loss, Direct Payments and Service Users'.

A revised Care Pathway is currently under development, with the aim of creating an holistic approach to the needs of people with hearing loss, including meeting their emotional, mental and practical needs. The intention is to create a pathway that incorporates all agencies working in the field and to reconfigure existing services in order to promote best practice and eradicate the 'postcode lottery' of service provision.

The Pathway plots the referral stages on the journey from diagnosis to full rehabilitation for people with acquired hearing loss.

There is also a children's services Care Pathway under development.

It is vital that the role of the voluntary sector is recognised and resourced to enable people with hearing loss to access the full range of services at their disposal. The Pathway needs to be supported by waiting time targets, effective cross-departmental and interagency working, and a measurement of the impact of rehabilitation upon the individual and their family.

Coordinating services for people with tinnitus

Action on Hearing Loss has submitted a best practice pathway concept to the Department of Health, Social Services and Public Safety, based on the

recommendations of a working group of tinnitus experts and people with tinnitus.

The Tinnitus Strategy¹⁶ calls for a joined up approach across health, social services and voluntary sector agencies, swift referral target times to ENT services and a mechanism for emergency referrals to the supra-specialist clinic in Belfast.

The proposed pathway promotes a local approach, where every Health Trust has a trained Tinnitus Specialist, and a referral route into other forms of support. This approach will future-proof support for people in tinnitus in the light of the ending of specialist training in Hearing Therapy in the UK.

To date the proposal for a new locally-based tinnitus service has not been addressed by the Health and Social Care Board.

What needs to happen

The NI Executive should undertake a region-wide data collection exercise to identify accurate numbers of people with hearing loss, deafness, tinnitus and deafblindness.

Government and associated public services should collect data on people of all ages who are deaf, deafblind, have a hearing loss or tinnitus.

Government departments and public services should plan appropriate levels of service to meet the needs of people who are deaf, deafblind, have a hearing loss or tinnitus.

Government departments and public services should ensure that planned services are measured for their effectiveness.

The Department of Health, Social Services and Public Safety should develop pathways for people of all ages who are deaf, deafblind, have a hearing loss or tinnitus, from diagnosis, to include all relevant statutory and voluntary agencies in a joined up approach.

The Department of Health, Social Services and Public Safety should ensure that the Care Pathway is underpinned by policies and protocols around timeframes and referrals.

¹⁶ A Tinnitus Strategy for Northern Ireland, Action on Hearing Loss, 2013

The NI Executive should support an interdepartmental Duty to Co-operate in the provision of services to deaf children.

Relevant rights

Article 3: General principles

Article 7: Children with disabilities

Article 24: Education

1.3 children per 1000 in Northern Ireland are diagnosed with a hearing loss in Northern Ireland every year, primarily through the Newborn Hearing Screening Programme which was introduced in 2004.

40% of deaf children have additional needs.¹⁷

90% of deaf children are born into families with no previous experience of deafness.

Early intervention – deaf children

90% of deaf children are born into families with no previous experience of deafness and there is a substantial onus on statutory services to ensure that the information and support needs of the deaf child, the parents and the wider family are met as fully as possible. Early intervention including clear pathways to referral and signposting to services is crucial.

Positive and long lasting impacts can be made on the development of deaf children through parents being able to access peer support and detailed information about their child's condition. Family Support can make a significant difference in outcomes for deaf children. Family Support can include advice to families on benefits, health and social care support, education, parenting and family sign language.

¹⁷ Fortnum et al. (1996) Health service implication of changes in aetiology and referral patterns of hearing impaired children in the Trent region.

Case study

As a result of the New Born Hearing Screening Programme, many deaf children are diagnosed within a few weeks of birth. As part of the initial service pathway, referral is made to Sensory Impairment at the local Education Authority and parents are visited by a Teacher of the Deaf. This demonstrates a 'joined up' approach, which is a statutory requirement.

Voluntary agencies are included in the pathway in only a limited number of Trust areas.

Early intervention - Deafblind children

Many deafblind children are born with multiple difficulties including critical medical needs. All early intervention - medical, social and educational - must be in the context of their sensory impairments if their future development is not to be compromised.

For both vision and hearing, the earliest intervention is imperative. All children with sight and hearing impairments must be referred to the relevant professionals at the earliest stage. Families need to have access to good information, and must be signposted to the relevant support organisations.

Case study

The SENSE 'Fill in the Gaps Campaign', funded by the Western Health and Social Care Trust, provides a specialist deafblind outreach worker to support deafblind children and families via an early intervention programme.

"Mary has come on so well, since this service has started, the activities are great and such a good help to Mary's general development..... I have learnt lots from how to encourage communication; how to teach her things myself through games and discovery play. How not to over stimulate, how to develop her attention span - so, so much and every bit beneficial for Mary and myself." (parent)

Early Years

Many parents of deaf children experience difficulties in finding child care placements for their children. Many Early Years settings are either not set up for or do not have trained staff to cope with the additional needs of deaf children. There is also limited funding available for acoustic adaptation of child care placements.

There is a lack of deaf awareness and information around tackling access issues in early years settings that urgently needs addressed.

The lack of adequate, deaf-friendly child care can adversely impact on the ability of parents of deaf children to find employment.

Congenital deafblindness in children, i.e. where the condition has been present since birth or early life, affects all aspects of learning and development.

Currently in Northern Ireland the Sense preschool nursery is the only service offering specific provision for deafblind children and those with sensory impairments and additional disabilities, and is only utilised by a small number of children from the Northern and Belfast Health and Social Care Trust areas.

Families and children across Northern Ireland should have access to specialist early intervention services similar to the Sense nursery.

Access to Education for Deafblind children

The UNCRPD imposes responsibilities on Government to ensure equality of access to education for deaf, deafblind and hard of hearing people.

Children with congenital deafblindness are referred to in the rest of the UK as being 'multi-sensory impaired' (MSI).

An appropriately qualified teacher is one who has a post-graduate qualification in multi-sensory impairment. This is a mandatory teaching requirement for the support of deafblind children in England and Wales.

Currently in Northern Ireland some teachers choose to do this as a distance learning qualification to add to their own personal development, but it is not a requirement for any post in Northern Ireland.

As deafblindness is now recognised in Northern Ireland as a distinct disability (Disability Strategy, 2012), we call for all deafblind children to have the same educational support as those in England and Wales. The Department of Education should identify those teachers who are currently qualified and commit to the training of an appropriate number of additional teachers to meet the needs of the deafblind children. Currently most deafblind children are included in generic classes in special schools or are supported at a mainstream setting not necessarily appropriate to their needs.

Inclusion of Auxiliary Aids and Services in SENDO

The Special Educational Needs and Disability Order (SENDO) 2005 is the primary method by which the disability-specific education needs of children are met. For deaf and deafblind children negotiation on what supports are required at school and in Further Education and Higher Education remains the responsibility of their parent, with input from teaching professionals and others.

Auxiliary Aids include technology such as radio aids, Soundfield systems and computers. Auxiliary Services would include the provision of sign support in the classroom or specialist Teaching Assistance. Currently in Northern Ireland, Auxiliary Aids and Services are excluded from SENDO.

This exclusion of Auxiliary Aids and Services means that a deaf or deafblind child depends upon the SEN process, rather than a disabilityspecific process, to have their needs met.

However, the SEN process, and its dependence on the 'statementing' system is, by default, a deficit system, as it requires a child to be failing to progress in learning in order to receive services.

If a child's progress is deemed to be above the threshold for intervention, then provision is not guaranteed and becomes the responsibility of the individual school, despite the fact that provision of technical aids for deaf children can be very expensive.

However, this policy results in unintended consequences, as it effectively restricts services required by any deaf or deafblind child who is deemed *not* to be failing. A child who, as a consequence, might be a high achiever, could be substantially restricted by the SEN process, rather than by their own capacity.

Case study

Families with a deaf child may not receive support for the provision of a radio aid to assist their child in the classroom. One family felt their child would benefit from this support and spent some £1700 on purchasing the equipment. Including the provision of Auxiliary Aids and Services within SENDO would ensure that the disability needs of deaf and deafblind children are met, and that the children have the opportunity to rise to the level of their own abilities.

Attainment

Deafness is not a learning disability and deaf children can achieve socially and academically in the same manner as any other child. The Special Education system should aim to close the attainment gap between deaf children and their hearing peers and allow their full inclusion in education. Services for deaf children should focus on supporting the child's learning needs and be based on outcomes.

It is essential that the child's progress is reviewed on at least an annual basis.

Almost two thirds of deaf children in Northern Ireland fail to achieve 5 GCSEs at Grade A* - C, including English and Maths. This is compared with an overall figure of 62.2% for all children.¹⁸ This is by some distance the largest gap among the nations that undertake GCSEs.

There are substantial variations in deaf children's achievement between local Education Authority areas.

Case study

There are great variations in the support available to young deaf people across local Education Authority areas.

Recently one of the areas has been moving away from face-to-face Teacher of the Deaf support for young people to support for the Teaching Assistant and the classroom teacher.

This area has recently recorded lower attainment figures than elsewhere.

^{18 2012/13} School Leavers Survey

Quantification and Specification of Education Services for Deaf Children

Services to meet the needs of deaf children are primarily detailed in the SEN statement.

A revised SEN Code of Practice will be prepared by the Department at the same time as the SEN legislation is being prepared. To date there has been no consultation on the development of the Draft Code, and there are a number of areas of concern. Prime among these is 'quantification and specification' of services in the Statement .

Clause 4.21 of the Code of Practice stipulates that services listed in Part 3b of the Statement should "normally be specific, detailed and quantified (in terms, for example, of hours of ancillary or specialist teaching support)." However, common experience shows that services have been neither quantified nor specified, unless the Statement is challenged.

This specification and qualification of the service is effectively the parent and child's legal guarantee that the service will be provided. To move away from either would be a serious regressive move.

Case studies

The NDCS Family Officers provide support to parents of deaf children when seeking education services to meet the needs of deaf children in school. There are a substantial number of examples in which local Education Authority areas have not quantified or specified services.

Statements have included wording such as 'access to' services, rather than detailing the specific service required. NDCS interventions have substantially improved the education offer to children.

Many other organisations who support parents within the education system also report this lack of quantification and specification.¹⁹

¹⁹ CDSA: The state of SEN statements (2014)

Participation in primary and secondary education

The UNCRPD recognises the importance of the involvement of deaf children in decisions relating to their lives in Article 7. Many deaf children have difficulties communicating their opinions and engaging in discussions over many issues, including school.

It is particularly important that deaf children and young people are able to comment on and, indeed, challenge their schooling. Formal opportunities should be made available to deaf children and young people through their being assisted to access school councils, however, it is also important that they are helped to express their opinions when assessments are being completed, during reviews of SEN statements, and during the drafting of Transition reports.

What needs to happen

The Department of Education must urgently review the adequacy of current education services for deaf children in light of the considerable gap in attainment between deaf children and their hearing peers.

The Department of Education should recognise hearing loss and deafness as a complex educational need, consider the most appropriate assessments for deaf children and ensure that quantification and specification of services remains with the rubric of any replacement for the SEN statement.

The Minister of Education should seek Executive support for the introduction of Auxiliary Aids and Services in the Special Educational Needs and Disability legislation for Northern Ireland.

All deafblind children should have the same educational support as those in England and Wales, i.e. children should be supported from diagnosis by a teacher with an appropriate qualification in Multi-Sensory Impairment.

Health and Social Care should develop pathways for deaf children from the point of diagnosis, to include all relevant statutory and voluntary agencies in a person-centred and joined up way.

Health and Social Care to introduce specialist Family Support for the families of deaf children in every part of Northern Ireland.

Early Years staff should be trained in working with deaf and deafblind children.

Health and Social Care should ensure that information about services for deaf children is available on Health and Social Care websites and through Family Support Hubs.

Health and Social Care should offer Family Signing Classes to parents and families of deaf children, aged 0-4, who wish to communicate through the medium of Sign Language.

Families and children across Northern Ireland should have access to specialist early intervention services, similar to the Sense nursery for deafblind children.

The Department of Education should ensure there is a sustainable supply of Teachers of the Deaf to support young people through their education.

Transitions

For young people who are deaf or hard of hearing, transitions, such as the move from school to university or college, training or employment can be more complex than for their hearing peers due to the range of communication, attitudinal and institutional barriers they may face in these settings.

While transitions support is provided in schools, there are variations in the type of support offered across Education Authority areas and not all relevant professionals are involved in providing that support in a cohesive way.

Recent research²⁰ into transitions for young deaf people, found that, overall, young people who were still at school found it difficult to identify who provided them with information on options and supports available after school, and to talk about the nature of this information. This may highlight the lack of information they had received or, the limited impact or value of this information.

The research identified a number of areas where young deaf people are experiencing difficulties in the transition process:

²⁰ Opening Doors – Transitions Experiences of Young People with Hearing Loss in Northern Ireland, Action on Hearing Loss, 2014

- Limited access to information: Young people often lack full access to information, on the range of options available after school, support available in further or higher education or in- work entitlements.
- Limited access to qualified interpreters: The lack of qualified interpreters, and the high costs associated with these, impacts on the level of inclusion and understanding of young people and the ability of educators, trainers and employers to meet communication needs.
- A need for sustainable and coordinated planning: Gaps in information and supports were identified in schools, post-18 and after young people leave university or training. There is a lack of sustained or co-ordinated careers planning between and across different settings.
- Lack of confidence: Young deaf people often have low levels of confidence which impacts on their school and post-school experiences. This could also impact on their ability or willingness to request support in school, further and higher education, and work environments.
- Insufficient deaf awareness: Lack of deaf awareness was a major concern. This ranged from teachers at school through to Disability Advisors and Learning Support Offers in further and higher education.
- Limited participation of young people in decision-making processes: Despite policies and legislative frameworks to enhance young people's participation, their experiences often suggest that these are not effectively translated into practice.

Case study

"I thought that I was not clever enough to do anything and was going to fail at all things. I now know that is not right. The deaf employment advisor from Action on Hearing Loss knew what it was like because he was deaf too. I believed him and he helped me get confident again. Someone like him should go to schools and meet all students who are deaf and going to leave school soon to see what they can do for their future. I wish my friend Jason has known him. He has no job for 2 years now."

What needs to happen

The Department of Employment and Learning, Department of Education and the Department of Health, Social Services and Public Safety need to work together ensure that services are providing tailored, ambitious, positive support to young deaf people, equipping them with the knowledge, skills and confidence to enable them to make informed decisions which will affect the rest of their lives. All young deaf people should have an entitlement to transitions planning.

The transitions planning process should actively involve and engage young people and take their views into account.

A programme of preparation for leaving school should be developed, to include: information on multiple post-16 options; information and signposts on supports and entitlements; confidence building and life skills; work experience and taster days, visits to colleges, universities, training organisations, and talks from deaf role models.

Information on transitions should be made available in different formats, including BSL, written text and visual formats, and online.

A post-16 transitions support service should be developed where longterm, independent, young-person centred support and guidance is available.

Deaf careers advisors should provide independent careers advice.

There should be a more 'formal' mechanism for young deaf people to share experiences and learning with each other.

The Department of Employment and Learning should carry out a longitudinal study to map the interventions, and long term outcomes for young deaf people from leaving school onwards, to identify areas of best practice.

Access to Higher and Further Education

In 2006/07 there were 240 deaf students enrolled in Universities in Northern Ireland. In 2014 that number fell to 95.²¹

Very low numbers attend local Colleges of Further and Higher Education – statistics show that 0.37% of college students have declared a hearing loss. Prevalence figures show that 1.7% of 16-30 year olds will have a hearing loss.

²¹ Department of Employment and Learning

College	19 & Under	20-24	25 & Over	Total Deaf	College Total
BMC	28	4	49	81	34,159
NRC	31	6	40	77	19,488
SERC	125	15	57	197	32,112
SRC	32	11	81	124	30,046
SWRC	30	4	47	81	21,909
NWRC	12	5	13	30	19,092
TOTAL	258	45	297	590	156,806

Enrolments of Deaf/Hard of Hearing in NI Further Education Sector 2012/13

Source: FESR. Total number of people with disabilities in FE: 18,000

Recent research²² has identified the following to be key issues in relation to accessing further and higher education:

- There are relatively low numbers of young deaf people accessing further and higher education.
- Colleges and universities were concerned that they were not aware of a young deaf person's support needs until after they arrived. They were more likely to be aware if in contact with transitions services (which is dependent on the young person having a Statement).
- Colleges and universities were concerned that some young deaf people did not disclose hearing loss or get in touch with disability services at all or until it was too late.
- There is a lack of understanding that young people require and have a right to *qualified* interpreters.
- Young people experience recurring difficulties accessing qualified interpreters in further and higher education settings. This is exacerbated by the high costs associated with interpreters in context of limited funding and which subsequently impacts on quality of support for students.
- Support staff are often not deaf aware and there are low levels of sign language proficiency across further and higher education.
- There is a shortage of communication support workers and a lack of awareness of electronic notetakers.
- It is important to recognise social transitions and potential isolation in new settings.

²² 'Opening Doors' Research into the experiences of young deaf people in transition, Action on Hearing Loss & QUB, 2014

• There is widespread concern about what happens when young people leave college or university – who supports them?

Case Studies

"I attend college at Belfast Met and I have communication support. You may think I am happy to get this support. Yes I am, but I am not happy with the quality of the communication support I get. The interpreters are not qualified and are at Level 3 or 4 standards. This means they won't have the ability to interpret 100% and I am still missing out on important information."

"The main thing was the culture shock that arose as a result of going from a small deaf-tailored environment to the big bad world of university. While QUB at that time had some of the best support for deaf students in the UK, lecturers often misunderstood the purpose of radio aids, and social activities with hearing students were difficult. I tried to join a number of clubs but gave up because of deafness and communication issues."

"It's a lot harder for deaf people to even know what it is that they want and a lot of times they're told that they can't do this"

"Our bottom line is we won't stop anybody doing a course. We give them the choice of what they want to do but obviously there has to be some sort of end that you know. We would find it very difficult if somebody is profoundly deaf going into a course where they are perhaps working with children or it's not going to be safe for either them or the young people." (FE College)

What needs to happen

The development of more systematic and sustained outreach programmes by Disability Services and Learning Support Services with young deaf people as early as possible.

Accessible information (including information in BSL) about support services should be available on college and university websites and on campus.

College and University teaching and support staff should have continuing deaf awareness training and a knowledge of sign language.

Young deaf people should be informed of their entitlements in further and higher education settings.

Government must invest in training more qualified sign language interpreters to meet the need.

Further and Higher Education providers should consider the use of 'remote interpreters'.

Support for young deaf people should that meet all of their needs, for example, this could be both an interpreter and a notetaker.

There should be clear and direct communication between Disability/Learning Support Services, course tutors/teaching staff, and administrative staff in advance of a student starting a course.

Further and Higher Education providers should develop a 'peer mentor' scheme where a young deaf person can get support from other deaf students.

Support should be provided to young deaf people when they transition from further or higher education.

Employment

Relevant rights

Article 27: Work and employment

Careers guidance

Further research is required to determine the quality and impact of careers guidance provided to young deaf people in Northern Ireland.

However, much anecdotal evidence suggests that deaf people find careers guidance difficult to access, due to a range of barriers.

In the school system young deaf people are provided with careers advice in a range of ways. The level of guidance they receive depends on the approach taken by the school, and the knowledge of the individual advisor about deaf issues, courses and colleges which provide accessible study, or other options which young deaf people can access.

Transitions meetings at which career options are discussed, do not always involve a Careers Adviser.

Local deaf children who attend school in England do not have a Careers Advisor attached.

Outside of the school system, the Education, Careers and Guidance Service is not generally contacted by deaf people due to perceived barriers to access. Deaf people report that they are unsure of how to contact the service, and have concerns about whether they will be understood, or if communication support (such as interpreters) will be available.

Anecdotal evidence suggests that a common feature of careers guidance provided to deaf people is that they should lower their horizons and be more 'realistic' about what they can achieve. In many cases deaf people have been advised to pursue careers which are vocational rather than professional in nature, and given the subtle message that their deafness is a barrier to other careers.

Case studies

"The careers adviser told me that I have to do hairdressing but I don't want that...I thought I was not clever enough to do anything and going to fail at all things. I felt lost and did not know about help".

"The key is 14-18 and is about raising aspirations amongst that group of young people it's that university should be an option. ... It's that many careers advisors and transitions officers aren't always maybe pushing university as an option for some groups of young people" (University representative)

What needs to happen

Government should carry out an analysis of the nature, quality and impact of careers advice provided to young deaf people in terms of their longer term outcomes.

A consistent approach to the provision of careers advice across Northern Ireland.

Best practice guidance should be developed, in partnership with young deaf people and deaf organisations, on the provision of accessible careers advice and guidance.

The Careers Advice and Guidance service should ensure a ring-fenced budget for the provision of registered communication support.

Careers advisors should be supported by a registered communication support professional.

The Careers Advice and Guidance service should work in partnership with specialists and establish referral procedures.

The Careers Advice and Guidance service ensure their service is accessible, by providing an SMS facility, working loop systems, frontline staff trained in deaf awareness.

Access to employment and training

In 2011 there were 130,500 adults of working age in Northern Ireland who have a hearing loss, of whom 4000 have severe or profound deafness.²³

Analysis of the Labour Force Survey, found that people with hearing loss were less likely to be employed than people with no long-term health issue or disability.²⁴

Severely or profoundly deaf people are four times more likely to be unemployed than the general population.²⁵

Research amongst working people with hearing loss showed that 78% of the respondents rated employer attitudes as being the single most important barrier to employment.²⁶ Other common barriers were: not knowing where to access support or advice (64%), and difficulty accessing funding for adjustments or equipment (47%).

Benefit claimants are expected to demonstrate a willingness to work, often via participation in voluntary work or work experience. To avail of these opportunities deaf and hard of hearing people require a range of support mechanisms, which carry a cost. Therefore a government scheme, comparable to Access to Work should be put in place for those in voluntary work or work placement. Without the supporting resource it is pointless for someone with hearing loss to take part in such schemes.

Evidence provided by young people in transition²⁷ from school to the workplace shows that they are not always aware of their entitlements, for example, to request adjustments for interviews, or types of support they may be able to access when in jobs (i.e. what employers must do). Other findings showed that:

There are relatively low numbers of young deaf people accessing mainstream employment and training programmes;

There are low levels of specific deaf awareness training and sign language proficiency across mainstream employment and training programmes; Mainstream providers are not always sure how best to support a young deaf person, or who to contact and how to book communication support.

²⁵ Facts and Figures, Action on Hearing Loss 2011

²³ Facts and Figures, Action on Hearing Loss 2011

²⁴ 2 Coleman, N., Sykes, W. and Groom, C. (2013) Barriers to employment and unfair treatment at work: a quantitative analysis of disabled people's experiences, EHRC.

²⁶ Unlimited Potential, A Research Report into hearing loss in the workplace, Action on Hearing Loss, 2014

²⁷ Opening Doors, A Research Report into the experiences of young deaf people in transition, Action on hearing Loss NI, 2014

Case studies

"As soon as they see the hearing aids they can't get me out of there fast enough...they assume because I can't use the phone, I can't do the job."

Peter is 39 years old and severely and progressively deaf. He had been unemployed for 2 years. He was worried about losing his benefits, and has had negative experiences in the past in seeking employment. Through the Action on Hearing Loss Employability Programme Peter attended confidence building and assertiveness training, was assisted to create a CV, and provided with one-to-one support in preparing for interview and coping with hearing aids with confidence. The Programme secured a work placement for Peter with Belfast City Council and upon using his CV to apply for a full time position, was successful in securing a job.

What needs to happen

Training providers and employers should be trained in deaf awareness.

Support is needed for young deaf people when they transition from training and employment programmes.

A work mentoring programme should be developed which matches young deaf people with a mentor in the relevant career area and who can provide ongoing support and advice.

Employers should ensure their recruitment practices are accessible, by ensuring that reasonable adjustments are made at the application and interview stage and that interview panellists are deaf aware.

Government needs to provide greater opportunities for work placements for deaf people across a range of professions as a route to work, and support employers in providing these.

The 'Access to Work' programme

Too many employers and people with disabilities are unaware of the Access to Work programme, yet it will provide a significant contribution towards communication support costs for someone with hearing loss in a working environment. It is vital for the Department of Employment and Learning to raise awareness of Access to Work as many employers view the recruitment of deaf people as an additional cost to them.

The Access to Work programme is not available to provide support for anyone carrying out work placements, or voluntary roles as part of their pathway to employment.

Access to Work is also not available to anyone working less than 8 hours a week for a single employer, which creates a barrier for deaf people who provide freelance services, for example, as translators or trainers.

In the 'Enabling Success' suggested Framework for Action, promoting work and increasing access to pre-employment and in-work support will be hindered by the absence of communication support funding for deaf volunteers or those on placement.

Case studies

In 2013 only 92 profoundly deaf people across Northern Ireland were using Access to Work support to enable them to work.

"Through the 'Bridge to Employment' scheme, I was assessed for an amplified for the call centre telephone system which allowed me to fully take on the role in my first full time job role. Access to Work provided the funding and the company were able to buy the equipment for me."

What needs to happen

The Department of Employment and Learning 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.

Hearing Loss in the Workplace

With increases to pension and retirement ages, the number of people with hearing loss in the workplace will increase.

Losing your hearing can be extremely distressing and many people don't want to admit they have a hearing loss which can affect a person's confidence and generate fears about job security.

The culture of an organisation influences the support mechanisms available and the way that managers and colleagues react. It is most common for managers to be broadly supportive but unlikely to take action, with people often reporting that their managers were negative in their reaction, even discriminatory.²⁸

Participation in meetings are a problem due to background noise and difficulties in lipreading, and employees report anxiety around having to use a telephone, and a lack of confidence in seeking adjustments.

Hearing loss can also force people to resign or retire early, or be made redundant.

People with hearing loss can become very isolated in work resulting in a range of challenges, including sick leave. Hearing loss is cited as the second highest reason for sickness absence in the workplace.

Case study

"The HR people said to me...even if we make reasonable adjustments for you, whatever they might be, after that we reserve the right to either move you to another post which could be at a lower rate of pay or indeed terminate your employment. That was the level of support from HR."

"I talked to my line managers and they were good and in fact one of them said something that helped me more than anything else ever has done. She said I had to tell the rest of the staff...because that would put some of the responsibility onto them as to how they communicated with me, and that's the single most helpful thing that anybody has ever said to me."

Underemployment

Research conducted in 2006²⁹ found that only 63% of people with hearing loss were employed, compared to 75% of the population as a whole and

²⁸ Unlimited Potential, A Research Report into hearing loss in the workplace, Action on Hearing Loss, 2011

²⁹ Opportunity Blocked, RNID, 2006

that people with hearing loss in work experienced worrying levels of prejudice, intolerance and patronising behaviour. It also appears that those in employment tend to be in lower skilled jobs and earn less than their hearing peers and reported discrimination at work.³⁰

Disabled people are generally afforded low status in the workplace, and the main barriers in terms of achieving a fulfilling and satisfactory employment arise from 'inappropriate myths and stereotypes, environmental barriers, and limited access to assistive technology.'³¹

Disabled people earn considerably less than their able-bodied peers, tend to have incomes below the poverty line and are more likely to take early retirement.³²

Disabled people are more likely to work part time and are usually on a lower hourly wage than their non-disabled counterparts, and in addition face widespread, multiple discrimination in the labour market.³³

Case study

"In the past I have had jobs working a shop part-time and an IT call centre. The shop environment was tough going. I felt I was always given the lower rank jobs, was not treated as an equal, and always reported to the boss for things I did not do. It really frustrates me that there is not enough support for those people in employment - those not getting treated fairly."

What needs to happen

Organisations should take steps to create a culture that support people with hearing loss through training, procedures and information for all staff.

Government must work to raise awareness of the legal rights of deaf people and employer responsibilities under the law.

³⁰ Shield (2006)

³¹ Braddock and Bachelder, 1994:1

³²Barnes & Mercer, 2005

³³ European Commission, 2001, Prime Minister's Strategy Unit, 2005

Audiology services should provide information and signpost working people to other sources of support such as equipment and technology, lipreading classes and Access to Work.

People with hearing loss must be encouraged to actively seek information and support, and inform their employer about their hearing loss and what adjustments they require.

Health

Relevant rights

Article 25: Health

Article 26: Habilitation and Rehabilitation

Article 4: General obligations

Access to Health Services

Research carried out by in 2009³⁴showed that less than half (47%) of the GP practices surveyed had made 'reasonable adjustments' specifically for people with a sensory disability, despite the provisions of the Disability Discrimination Act 2005.

The findings revealed that there was a general lack of awareness of the needs of people with sensory disability when accessing primary care, a lack of training for staff in this area, a shortage of suitable assistive technology and gaps in policy and procedures to meet the communication and mobility needs of patients with a sensory disability.

Poor accessibility to services has a detrimental effect on those who need them. For example, 2013³⁵ research indicated that one in seven respondents (14%) had missed an appointment because they had not been aware of their name being called in the waiting room. Around one-quarter (26%) had been unclear about health advice they were provided with. It found that patients who felt unclear after a consultation attributed the misunderstandings to their GP not facing them (64%) and not always speaking clearly (57%).

The Health and Social Care Board has developed guidance for GPs in improving access to their services for people with sensory disability. However, the practical implementation of the guidance and monitoring of its impact is key to ensuring the people with hearing loss receive equal access to primary healthcare.

Case studies

³⁴ Is It My Turn Yet? Action on Hearing Loss NI, RNIB and the British Deaf Association, 2009

³⁵ Access All Areas, Action on Hearing Loss. 2013

"Many people are ignorant as to how to speak to a deaf person. Recently a consultant could only shout [at me] when all that was needed was to speak slowly and clearly."

"When I was moved on to a ward the information about my hearing loss was not transferred onto the board above my bed."

Health inequalities

Researchers have found that 'hearing impairment inevitably affects healthrelated quality of life'.³⁶ A number of studies have shown that people who are deaf or who have a hearing loss can experience lower health-related quality of life: higher distress, anxiety, depression, somatisation, social isolation and loneliness with negative implications on emotional, mental, and physical health.³⁷

People with hearing loss can also be found to have higher levels of ill health, for example: there may be a link between smoking and hearing loss³⁸; there have been indications of a relationship between obesity and hearing loss; and some ambiguous findings around hearing loss and hypertension.^{39 40}

This evidence suggests a need to tackle risk factors, including smoking, obesity and high blood pressure, in people with hearing loss and the signing community. One reason for these associations might be that public health information and programmes do not reach these groups.

There is evidence that people who are deaf – sign language users in particular – are not included in prevention services. Studies have found that deaf people are at greater risk and have lower levels of health knowledge than others. For example, a recent survey in Rochester, New York⁴¹, indicated a greater cardiovascular risk among deaf participants.

Similarly, US research suggested that knowledge about cardiovascular disease among patients who are deaf was considerably lower than that of

³⁶Agrawal, Platz and Niparko, 2009; Fransen et al., 2008; Helzner et al., 2011; Shargorodsky et al., 2010, Nachtegaal *et al*, 2009, Bridges, 1998, Mulrow *et al*, 1990

³⁷ Cost benefit analysis of hearing screening for older people, RNID 2010

³⁹ Piroddaet al., 1999; Rosenhall and Sundh, 2006

⁴⁰ Shargorodsky et al., 2010

⁴¹ McKee et al., 2011, Impact of communication

the general population: in a survey, 40% of American Sign Language users could not list any symptoms of heart attack; 60% couldn't list any symptoms of stroke⁴².

Barriers identified include a lack of healthcare information, lack of access due to language and communication challenges, financial constraints and stress⁴³. It is important that prevention services are designed with people with hearing loss and deaf users of BSL in mind.

Without appropriate support it is extremely difficult for deafblind people to lead an active healthy life. Mobility, shopping and cooking healthy food and keeping mentally active are all a challenge. Research has shown that deafblind older people have higher rates of common conditions associated with increasing age⁴⁴. This includes an increased risk of stroke (3.6 times higher), arthritis (2.2 times higher), heart disease (2.5 times higher), hypertension (1.5 times higher) falls (3.0 times higher) and depression (2.7 times higher).

Case studies

In 2012, an Action on Hearing Loss project aimed at increasing awareness of healthy living hosted a Health Fair offering a range of health checks to deaf people who had not taken up such opportunities before. On receiving a check-up three people were referred to attend hospital immediately due to serious concerns over their coronary health, which had been previously unidentified.

Deaf Connections (Scotland) recognised that traditional methods of health promotion were not reaching members of the deaf community effectively and what was required was to work directly with deaf people to identify their health needs and prepare programmes to tackle these. Training and support are provided to enable workers with deaf people to deliver a range of health programmes to the deaf community.

Promotion of hearing health

⁴² Margellos-Anast, Estarziau and Kaufman, 2006

⁴³ McKee et al., 2011, Perceptions of cardiovascular health

⁴⁴ (Crewes and Campbell, 2004).

Exposure to excessive noise is the major avoidable cause of permanent hearing loss worldwide, according to the World Health Organisation (WHO).

Research⁴⁵ has shown 73% of people who have ever been to a club, gig, concert or festival have had ringing in their ears after a night out or the morning after.

81% of MP3 users tested in Belfast⁴⁶ were listening to music louder than 85 decibels which, according to WHO, can cause permanent damage to hearing over time.

The Medical Research Council has estimated that as many as 4,000,000 ⁴⁷ adolescents are at risk from hearing loss due to listening to amplified music in Great Britain.

The Health and Safety Executive estimate that one million UK workers are exposed to noise levels that might damage their hearing.

Damage to hearing from noise cannot be repaired. It is irreversible in humans – only birds and certain types of fish can grow back damaged ear cells.

Case studies

"We've been out a few times, and we've said 'it's not loud enough'. It needs to be louder."

"Well I've never really minded it...when my ears have rung 'cause that's the sign of a good night, it's a bit like an endorsement or whatever..."

What needs to happens

The Department of Health, Social Services and Public Safety must put in place accessibility quality standards and a monitoring system, by which GP services and other primary care services can be measured for their levels of access and held accountable.

⁴⁵ RNID, 2002

⁴⁶ RNID NI, 2008

⁴⁷ Medical Research Council (Institute of Hearing Research, 1986)

The Public Health Agency must ensures that public health information and health promotion campaigns are accessible to sign language users. deafblind people and people with hearing loss.

Information, guidance and health promotion campaigns around other longterm conditions should be provided for people with hearing loss and deaf people who use British Sign Language (BSL) in a format that they can access.

The Department of Health, Social Services and Public Safety should measure the impact of inaccessible healthcare information on the health and wellbeing of deaf people in the context of the UNCRPD.

Employers should understand and meet their obligations under Noise at Work legislation and know how to meet them, and to promote protection to employees exposed to noise in the workplace.

The Public Health Agency should raise awareness with the general public of the dangers of over exposure to loud noise.

The Public Health Agency should encourage the general public to value and protect their hearing.

Hearing screening for adults with 'acquired' hearing loss

Deafness and hearing loss are most prevalent in the older population. 55% of people over 60 are deaf or hard of hearing.

Hearing aids can limit the impacts of hearing loss. The benefits of hearing aid use- significant improvements in emotional, mental, and physical health, as well as general quality of life- are strongly supported by research findings.48

Diagnosis of age-related hearing loss is opportunistic and ad hoc and there is on average a 10 year delay in people seeking help. Evidence suggests that GPs fail to refer 45% of people reporting hearing problems.⁴⁹

As a result, an estimated four million people in the UK have unmet or unrecognised hearing loss. The majority of these people are likely to be

⁴⁸ Newman et al, 1991, Kochkin and Rogin, 2000, Abrams 2002, Bridges, 1998, Mulrow et al, 1990, The National Council on the Aging, 1999, Newman *et al*, 1991 ⁴⁹ Hearing Matters, Action on Hearing Loss, 2011

over 60 years old. It is estimated 115,000 people in Northern Ireland could benefit from a hearing aid and are not currently using one.

With the linkage to other personal health conditions and social problems, such a scale of untreated hearing loss results bears a substantial cost to the NHS health and social care services.

A hearing screening programme for older adults would:

- Identify people who could benefit from hearing aids;
- Identify them early, when they find it easier to adjust to hearing aids and will gain more benefit and more years of improved quality of life;
- Help GPs to make more appropriate referrals.

Research has shown that a hearing screening programme for people aged 65 would save a total of £2 billion over ten years at a cost of £255 million in the same period.⁵⁰

As well as providing economic benefits, a screening programme would set out clear routes for referral and treatment for adults. This would enable earlier access to hearing aids and other services and support.

Case studies

A cost benefit analysis of a hearing screening programme carried out by Action on Hearing Loss and London School of Economics in 2010, showed that the benefits of hearing screening for older people clearly outweigh the costs. At a cost of £255m over 10 years, a hearing screening programme for over 65s could save £2bn, representing a benefit cost ratio of more than 8:1.

"Having hearing aids has improved my quality of life. Now that I wear them, I think it was ridiculous that I put off getting them".

"I am now in the second week of being the proud owner of my hearing aid and it has made such a difference to my everyday life and also my social life."

"I attended a past pupils function at my old school and did not have a problem talking within a group which I would have avoided before and would only have spoken to people on a one to one basis."

⁵⁰ Cost benefit analysis of hearing screening for older people, London Economics / RNID, September 2010

"Each day I notice something small that I have not heard for ages... It is the small things that have made such a difference, one knows it is windy but I had forgotten the noise the wind makes blowing through the leaves on the trees and hedges"

Audiology Quality Standards

Quality standards for adult audiology services were introduced in Northern Ireland in 2013. This is welcome step forward in ensuring that patients receive a quality hearing aid service, and that audiology staff are supported to deliver a quality service.

It is important that audiology services are provided with the necessary resources to enable them to meet their obligations under the Quality Standards and that their progress is monitored and reported on.

Research in 2014⁵¹ indicates that some audiology services in Northern Ireland are experiencing increasing patient waiting times, a shortage of staff and difficulties in recruiting and retaining staff. This has impacted on their ability to implement Quality Standards. Some audiology patients reported in a recent survey⁵² they were not given information on cleaning, re-tubing and repairs to their hearing aid. A significant number reported that they do not know of other services and organisations that could help them, or where to go for specialist equipment.

Working in partnership with voluntary sector service providers can provide an holistic approach to hearing care, where hearing users can benefit from the experience of peers, have access to a wide range information at the point of treatment, and support in improving communication and relationships within the family.

Case studies

"I informed the receptionist I was deaf and had an appointment. I was told to wait at the waiting room. Five minutes later, I didn't realise the audiologist was calling my name and I eventually realised she was calling my name after realising other people waiting hadn't moved from their seats."

⁵¹ Under Pressure, Action on Hearing Loss, 2015

⁵² Northern Ireland Audiology Services Patient Survey 2014 - A Survey of Audiology Patient Experience up to five years following the fitting of a Hearing Aid, Action on Hearing Loss, 2015

"I tried to understand the audiologist during a conversation about my hearing aids. I didn't understand her as she spoke too fast and couldn't sign"

"I always try to attend my mother's appointments with her to explain what the specialist is doing and saying, and I write the instructions on the front cover of the booklet for her. I dread when it will be my turn to attend these sessions – I won't have a son or daughter to help me."

Paediatric audiology

In Northern Ireland, there are currently no quality standards for the specialism of paediatric audiology, despite there being standards for Adult Services. It is essential that quality paediatric standards are developed in line with developments in GB.

Training in audiology

There has been no training course available in Northern Ireland to anyone wishing to pursue a career in audiology, for a number of years. This has led to a shortage in the supply of local audiologists, which is impacting negatively on the ability of audiology clinics to deliver on some aspects of the new Audiology Quality Standards. It will also impact on future workforce planning for the service.

Issues said to be precluding the course from progressing locally include a shortage in the number of hospital audiology clinics accredited to take on student placements, considerations around demand for the course and within the workforce, and the need for support from the clinical community for such a course.

With the number of people with hearing loss set to grow to over 400,000⁵³ by 2031 in Northern Ireland, it is essential that audiology services are adequately resources to meet the growing demand.

⁵³ Prevalence rates derived from Davis (1995) applied to 2008 ONS Population projections for Northern Ireland."

Hearing aid aftercare

Many people who has been diagnosed with hearing loss and fitted with a hearing aid experience difficulties in adapting to their hearing aid, in using the aid correctly, and in getting benefit from their hearing aid.

66% of respondents to a survey in 2009⁵⁴ reported that they had some degree of difficulty in using their hearing aid when they first received it.

This was attributed to a number of factors, including a lack of information and practical guidance at the time of fitting, attending the fitting appointment alone and not retaining the information given at the time, a lack of follow up appointment, a reluctance to return to seek help from audiology departments, a broader issue relating to coming to terms with hearing loss, not being aware of organisations providing support, poor health or arthritis, difficulties in adapting to technology, and other issues.

Good aftercare is essential to enable people to adjust and get the full benefit from their hearing aids. It is vital that information, emotional support and practical guidance is made available to people with hearing loss and their families, as soon as possible after diagnosis and treatment.

A survey of audiology patient experiences in Northern Ireland carried out in 2014⁵⁵ found that the majority of patients said that they had not been signposted to other sources of support or given information on assistive equipment. A third said they were experiencing problems with their hearing aids, and 13% were seeking further help, demonstrates that Audiology services need to provide information on support existing outside their clinics, i.e. social services, lipreading classes, and voluntary sector services.

Case study

Action on Hearing Loss has been providing aftercare services to people struggling to use their hearing aids since 2007 through a community-based approach, supported by trained and qualified volunteers with a mix of outreach, domiciliary and drop in services.

Aftercare services include re-tubing, ear mould cleaning and battery replacement; basic training for hearing aid users, families and carers on hearing aid maintenance and usage; signposting to other statutory and

⁵⁴ Out of the Drawer, 2009, RNID Cymru

⁵⁵ Northern Ireland Audiology Services Patient Survey 2015, Action on Hearing Loss

voluntary services and support groups; coping strategies and communication tactics; and an introduction to assistive equipment.

Hearing aid users who have accessed this service report increased use, benefit and satisfaction with their hearing aid; easier and speedier access to hearing aid support in their local community; increased awareness of local service and improved confidence and communication skills, leading to reduced isolation.

A Social Return on Investment evaluation of the Hear to Help service has demonstrated a £10.34 return for every £1 spent.⁵⁶

What needs to happen

The Department of Health, Social Services and Public Safety should introduce hearing screening for people aged 65.

The Department of Health, Social Services and Public Safety should ensure that Audiology departments are supported to comply with Quality Standards in Audiology, and monitor and report on progress annually.

The Department of Health, Social Services and Public Safety should develop quality standards in paediatric audiology.

The Department of Health, Social Services and Public Safety should carry out a workforce planning exercise to identify numbers of audiology professionals required now and in the future.

The Department of Health, Social Services and Public Safety should identify and support a training route to meet the future workforce requirements for audiology services.

The Department of Health, Social Services and Public Safety should develop partnerships with the voluntary and community sector to ensure that people fitted with a hearing aid are provided with information, signposting and services to enable them to make the best use of their hearing aid, to manage their hearing loss, to maintain communication with family and friends and at work, and to lead a full and normal life.

⁵⁶ Hear to Help. An SROI report. F. Boyle, Oct 2014

Reablement and rehabilitation

Hearing loss leads to significant changes in methods of communication and affects every area of life including relationships, work, financial security, social situations, and even personality. Whether the loss has been sudden or gradual, usual communication methods which have been taken for granted can change to become stressful, exhausting and embarrassing.

The stigma attached to hearing loss, and the attitude of others, together with one's own perceptions, can result in low self-esteem among people who have hearing loss.⁵⁷

Hearing loss can have significant negative effects on family relationships, affecting general communication between partners, siblings and between parents and children. One study showed that a majority of couples and families were placed under considerable amounts of strain as a result of hearing loss in the family. Family members who have related to each other as hearing people have to find new ways of communicating which can feel strange and lead to frustration.

It also causes difficulties in day-to-day life. For instance, it can cause challenges in commonly-visited environments, such as a doctor's surgery, shops, restaurants, banks and generally any public places.

A range of early interventions are needed to help people take back control and manage their hearing loss and relationships better on a day to day basis. The sooner these interventions are offered the more likely that some of the longer term negative effects associated with hearing loss can be prevented.

In order to ensure that people learn to cope with their hearing loss, 'aural rehabilitation' is recognised as one kind of effective intervention.

'An aural rehabilitation programme is in many cases more effective if it includes both lipreading and auditory training and should be available to every adult who requires help as soon as possible after a hearing impairment has been ascertained.... It is said to reduce "hearing-loss-induced deficits of function, activity, participation, and quality of life'⁵⁸

Peer-led programmes focusing on self management techniques and communication strategies have demonstrated increased feelings of

⁵⁷ Shield (2006)

⁵⁸ Watts & Pegg, 1977

independence and greater self confidence for people with acquired hearing loss. Intensive residential programmes for people with severe/profound hearing loss and family members/friends have shown marked benefits for all participants in several areas of life, including psychological adjustment, state of health, quality of life, communication effectiveness and social functioning. ⁵⁹

Deafblindness, or Dual Sensory Impairment, affects different people in different ways. When communication is limited, people become socially and emotionally isolated. When people can't get around by themselves it affects their confidence, independence, social and daily living skills. Without access to information, people can't make informed decisions and this leads to a further loss of independence. If appropriate and timely services are provided at the right time, the need for greater provision at a later stage can be reduced.

Sudden loss of a sense, due to illness or accident, can be devastating and have a significant impact on a person's life, therefore it is vital that individuals have access to the appropriate support to help them to adjust, both emotionally and practically.

Progressive sight and hearing loss is common with ageing, and may for some time be unrecognised, however, over time, this combined loss will have a significant cumulative impact on a person's communication with others, their access to important information and their mobility.'

Case studies

"I don't see a lot of my family. I don't think my daughter realises how deaf I am. I can tell when she gets impatient with me from her body language....When my brother comes to visit, if I don't hear the doorbell, he goes home without seeing me."

An ex-opera singer, now in her 70's, has lived for several years believing she could never sing again because of her hearing loss. After attending a Hearing Link Intensive Rehabilitation Programme with her sister, she took part in an after dinner singalong and gave this feedback "You are all honoured - who would have thought I would sing again! This week I have achieved getting my independence and confidence back". Another participant commented that she was "looking forward to the future now".

⁵⁹ Sherbourne et al, International Journal of Audiology, 2002

Communication strategies

'Managing hearing loss' involves developing strategies that support lipreading, techniques to further enhance communication, including learning about services, equipment and assistive technologies, and practical steps to help people to effectively manage their hearing loss.

'Lipreading' is the ability to recognise lip shapes and patterns and to use context to fill gaps in conversation in order to maximise communication, which is vital for people with acquired hearing loss. It enables them to supplement their remaining hearing with an enhanced ability to communicate and plays a key role in their ability to adapt to their hearing loss.

Recent research⁶⁰ has demonstrated that combined lipreading and managing hearing loss courses provide a package of support that is vital in enabling people to successfully adjust to and manage their hearing loss. They help to reduce feelings of isolation and increase feelings of confidence, control and self-assertion.

The Health and Social Care Board has recently invested in the training of local lipreading tutors, and this is to be welcomed. However, in order to ensure that people with hearing loss benefit from lipreading, lipreading and managing hearing loss classes need to become an integral part of the patient pathway.

Case studies

"Where I would have shied away and would not have said I couldn't hear, I now say 'I'm sorry, but I am hard of hearing and I can't hear you'. I'm not scared to do that now."

"One lady said after the lipreading class that she got into the car with her husband, broke down and started to cry 'this is the first time that I have felt that I am somewhere that people understand.""

Feedback after attending first sessions with other people with hearing loss included "Deafness is nothing to be ashamed of", "It is possible to live a normal life. Others have done it" "Finger spelling ...will be really useful in all situations where communication is difficult"

⁶⁰ Action on Hearing Loss 'Not Just Lip Service' 2013

Dual sensory loss or deafblindness

There are a number of different types of deafblindness:

- congenital deafblindness, where people are born deafblind and who form a minority of the total number of deafblind people;
- profoundly deaf people who become deafblind;
- people with acquired hearing loss, or 'deafened' people, who lose their sight;
- people with sight loss who lose their hearing;
- people who acquire a sight and hearing loss for reasons other than the ageing process, for example, through injury or illness;
- age-related deafblindness, where both sight and hearing loss occur as a result of the ageing process. This last group form the largest number of people who are deafblind, but yet remain a hidden group.

Communication varies significantly within the deafblind population – some people use the Deafblind Manual Alphabet, some have sign language as a first language or use speech, and many people do not have specific deafblind communication skills at all.

Traditionally, service provision has focussed on one sensory loss over the other, depending on which is causing most difficulty at the time of the intervention.

There is no definitive record of the numbers of deafblind people in Northern Ireland. A 2014 research project carried out by the Western Health and Social Care Trust and Sense identified a wide variance between the numbers of people estimated through different prevalence statistics and the numbers of people presenting and identified through existing Health Trust records. This points to the need for a universally agreed and reliable data collection method, and increased public awareness to enable deafblind people to self-identify.

In England the Care Act 2014 has been introduced with the aim of creating a single, consistent route to establishing an entitlement to public care and support for all adults with needs for care and support.

This strengthens the existing legislation introduced in 2002. It gives deafblind people, and others as yet undiagnosed, the right to be assessed for their care and support needs, and for Social Workers to be appropriately trained to carry out such assessments.

There is no such equivalent legislation in Northern Ireland.

As the population ages the incidence of deafblindness is going to increase. Given that the majority of older deafblind people will have an acquired hearing loss, a significant majority will communicate using speech and will need access to hearing aid technology and support with using this technology.

In addition, other long term conditions can have associated communication difficulties, such as stroke and motor neurone disease.

The impact of an additional sensory loss must be recognised, both in terms of the direct impact of that condition and also the compound impact on functioning caused by a second sensory loss. These people will have increased difficulties with mobility, communication and access to information.

For people with hearing loss who have developed communication strategies based on visual cues (e.g. lipreading, use of technology etc.) a secondary loss of sight has significant implications with the need to review and add new strategies and techniques. Implications can include exhaustion, dealing with psychological impact, implications for relationships, employment, social life etc.

Case studies

Scene Enterprises, an acquired deafblind awareness and campaigning organisation, reassessed 100 people on the Visually Impaired Register in Northumberland, and identified that 63 of those people had an unrecorded hearing loss.

A young Deaf mother was admitted to a mother & baby unit for assessment. She was ignoring her baby when he was obviously distressed. It transpired that she could not see him unless he was directly in front of her. Usher's Syndrome was diagnosed. "One thing that frustrates me hugely, is the 'either / or' nature of accessibility. Support is given for people with sight impairment but assumes you can hear well. Conversely, support for deafness assumes you can see well."

What needs to happen

The Department of Health, Social Services and Public Safety should undertake research to identify the most effective ways of delivering lipreading and managing hearing loss support.

The Department of Health, Social Services and Public Safety should ensure lipreading and managing hearing loss classes are designed into the patient pathway for people with hearing loss.

Lipreading classes must be provided to people with hearing loss at no cost to them, across Northern Ireland.

Outcomes for people with hearing loss who attend lipreading classes should be measured.

The Department of Health, Social Services and Public Safety should address the long term reablement of people with hearing loss and measure the outcomes.

The Department of Health, Social Services and Public Safety should establish a database of deafblind people in order to plan services to meet need.

The Department of Health, Social Services and Public Safety should increase public awareness of deafblindness to enable deafblind people to self-identify.

GPs and other healthcare professionals, including domiciliary care staff, should be aware of deafblindness, to be able to identify older people with failing dual senses, and refer to appropriate support services.

Social workers should be trained in carrying out assessments of the needs of deafblind people.

Where required, specialist equipment, adapted services or specialist one to one support for deafblind people should be provided.

Information should be provided in the most appropriate format for the deafblind person.

The Department of Health, Social Services and Public Safety should carry out a review of the impacts of Department of Health Guidance, the Care Act and Section 7 legislation, currently in practice in other parts of the UK, to inform the development of guidance and best practice for Northern Ireland.

Long term conditions

There are an estimated 15 million people in the UK with long-term conditions – conditions that can be managed but not cured - such as hearing loss, diabetes, asthma, sight loss, cardiovascular disease and dementia.

In many cases long-term conditions are linked to the ageing process. This means that a large proportion of people will have hearing loss, along with one or more other long-term condition. It is important that services setting out to prevent and manage other long-term conditions are designed with people who have hearing loss, and sign language users, in mind.

There is a need for specialist diagnostic tools, interventions and novel approaches to the delivery of services. In particular, the communication needs of people with hearing loss or deafness will need to be addressed to ensure that they receive effective care, especially where they also have other conditions that affect communication, such as dementia or impairments following a stroke. In conditions such as diabetes and hypertension, where patients can play a large role in self-managing their conditions, facilitating effective communication with health professionals is particularly important.

The Department of Health, Social Services and Public Safety introduced plans to improve the management of long term condition in 2009. These plans tend to consider long-term conditions in isolation and do not adequately take account of issues relating to hearing loss and deafness. For example, the Bamford Review of Mental Health and Learning Disability 1997 does not acknowledge the need to manage hearing loss in people with dementia.

Case study

Scene Enterprises, studied 100 people on the Visually Impaired Register in Northumberland and in addition to the 63 people with an unrecorded hearing loss, identified incidences of additional acquired communication disorders (ACD), such as Parkinson's, dementia, stoke, cancer and trauma. These conditions add to the frustrations and limitations of communication caused by deafblindness.

What needs to happen

GPs and all health professionals should be aware of the high prevalence of hearing loss and links between hearing loss and other long-term conditions.

The Department of Health, Social Services and Public Safety, the Health and Social Care Board, and Health and Social Care Trusts should recognise hearing loss and deafness in assessing, diagnosing and managing people with other long-term conditions.

Services for people with dementia, cardiovascular disease, diabetes and sight loss must take into account the needs of people with hearing loss and deaf people.

Government should fund research to develop better diagnostic tools, specialist services and guidance to support people with hearing loss and deaf people who also have other long-term conditions; and make sure these are used.

Mental Health in deaf and hard of hearing people

Deaf children and young people with mental health problems

Strong emotional health and well-being is particularly important for deaf children and young people. Deaf children often find expressing emotions difficult, and communications difficulties will often make the simplest frustrations stressful.

The developmental difficulties and social pressures affecting many deaf children can give rise to emotional, behavioural and adjustment problems (40-50% compared with 25% for the general population) which can continue into adult life.

If problems become critical a deaf child may require access to child and adolescent mental health services (CAMHS). Generic CAMHS should have a good understanding of childhood deafness and be accessible to deaf children. However, research has indicated that generic CAMHS lack the expertise and skills in deafness to fully and effectively support and communicate directly with deaf children⁶¹.

In Northern Ireland there is a need for a Specialist CAMHS for deaf children which should:

- Work closely with adult mental health services, where necessary, to ensure a smooth transition of care arrangements into adulthood with continuation of coverage and tailored support.
- Advise on appropriate care pathways for the minority of deaf children requiring inpatient assessment and treatment.
- Identify the most effective interventions for deaf children and disseminate this knowledge nationally.
- Develop partnerships with other agencies that work with deaf children, across health, social care, education and the voluntary sector
- Have the necessary expertise to promote deaf-friendly strategies for lifelong skills.

It is vital that specialist interventions are made early, during childhood and between the ages of 18 and 25, to prevent long term mental health issues developing.

Information on mental health needs to be accessible and made available at an early stage, and GPs need to be aware of the issues relating to mental health and deafness.

Deaf adults with mental health problems

Deaf people encounter the same range of mental health problems as the general population. However, they are also at increased risk of having complex and organic disorders, as many of the non-genetic causes of deafness, such as maternal rubella, neonatal jaundice, prematurity, birth

⁶¹ Beresford, B., Greco, V., Clarke, S., and Sutherland, H. (2008) An evaluation of specialist mental health services for deaf children, Research Works, 2008-02, Social Policy Research Unit, University of York, York.

anoxia and meningitis can be associated with a range of physical, sight and neurological problems.

Research has found a higher incidence of emotional, behavioural and adjustment disorders among people who are deaf than those who are hearing⁶².

People who are deaf currently face significant barriers when accessing mental health services. Mental health professionals are often not deaf aware, and do not understand deaf culture and the barriers that deaf people face in society⁶³, and services are often not accessible to sign language users.

There are very few BSL-fluent mental health workers, BSL interpreters or qualified lipspeakers who have the skills and experience to work in mental health⁶⁴. These barriers in accessing services means that mental health services are underused by deaf and deafblind people.⁶⁵ It is noted that deaf people with psychotic illnesses do not present to services.

Deaf sign language users are often not aware of psychological concepts that are understood in the hearing world. There is a need for a programme of psycho-education among the deaf community, beginning at an early stage.

While a specialist mental health service for deaf people has been operating in Northern Ireland since 2003, research in 2010⁶⁶ found that 72% of local GPs were simply not aware of it, and only 7% had referred anyone to it for support.

All of the staff in the specialist service are hearing, and the aspiration is to employ deaf mental health professionals, and in particular a deaf psychiatrist, who can have a level of understanding and empathy that hearing people simply cannot. There is also a need for deaf social workers and deaf community workers who have additional training and skills in mental health.

Case study

⁶² NHS Health Advisory Service (1998)

^{63 (}DH 2002; RNID 2004; Glasgow Caledonian University 2009)

⁶⁴ (du Feu and Fergusson 2003; Glasgow Caledonian University 2009)

⁶⁵ (Glasgow Caledonian University 2009).

⁶⁶ Is it My Turn Yet, 2010., Action on Hearing Loss NI and RNIB NI

"A couple of clients have said to me that they nearly didn't come to the first session because they were fed up with not being able to understand the audiologist/doctor/social worker but when they walked in and saw that I could communicate easily with them they felt such a sense of relief."

Deafblind people with mental health problems

Many children who are deafblind due to causes such as meningitis, rubella and extreme prematurity, also have learning disability. Communication is severely limited, except by tactile means. However, with intensive input, children can develop structured lives, with practical and social skills, meaningful relationships and pleasurable activities. Behavioural approaches can curtail the self-stimulating and repetitive behaviours that may occur. Families need early information and ongoing support.

The issues around the mental ill-health of deafblind adults are both complex and varied, although the majority of issues can be categorised as follows:

- 1. People whose 'frustrations' of living with acquired deafblindness has led to depression, anxiety and stress;
- 2. People with pre-existing mental ill-health issues, such as bi-polar disorder;
- 3. People who have developed dementia.

A number of studies have shown that stress and depression are very common consequences of deafblindness as deafblind people become isolated due to communication difficulties.

In the case of pre-existing mental health conditions, there is no evidence to suggest that deafblind people are any more likely than the rest of the population to suffer from a pre-existing condition.

However, as the population ages many people with already diagnosed mental ill-health conditions will subsequently become deafblind.

In the case of deafblind people who develop dementia, the challenge is for healthcare professionals to adjust their method of communicating and testing to accommodate the communication barriers that exist. Often no additional specialist skills are needed beyond good communication practice, but a lack of adjustment can impact on the reliability and accuracy of a diagnosis of dementia in deafblind people.

Case studies

Brian lost his sight and hearing after a medical accident and can now only see through a pinhole and is almost completely deaf.

"I can't cope in social settings anymore they are too noisy for my hearing aids." Brian has become a virtual recluse in his own home. "The idea of using a cash machine in the street horrifies me – I won't know who is watching. I worry about answering the front door so much I only answer it if I have a planned visitor and then only if we agree a password in advance of the person calling such as the gas man."

Brian is extremely depressed and emotionally vulnerable. He feels his life has been turned upside down. "I would love to be able to go out again and to have someone to have grown up conversations with, and to be useful to someone else."

William lost his sight and hearing in his 70's and his wife Mary has memory problems. He was a keen walker and had a hobby working on cars but that was some years ago. Now he sits at home, mostly stays in bed as he doesn't see the point in getting dressed. This worries Mary a lot. "I don't go out socially anymore or shopping as transport is a big problem for us. Mary goes for us. But she forgets so much these days. I can't answer the phone so Mary does that as well. She makes notes but then loses them."

Mental health impacts for people with acquired hearing loss

There is strong evidence that those with hearing loss have a higher prevalence of depression, anxiety and stress.

The rate of depression (using HADS⁶⁷ scale) in deafened people is nearly five times higher than general population, and four times higher in hearing partners.

Up to 40% of people with hearing loss experience mental health problems at some point – nearly double the 25% in the general population.⁶⁸

⁶⁷ Hospital Anxiety and Depression Scale

Rates for severe anxiety are two and half times greater than the average for the UK population, and one and half times greater for hearing partners.⁶⁹

Research shows that a range of factors influence mental health outcomes including:

- Losing hearing post-lingually, in particular, people who have been deafened
- Poor social and support networks
- Hearing loss not being effectively managed

Case study

"As a counsellor working with hearing impaired people, I take responsibility for making sure my clients can understand me. For some clients that will mean making sure the room is quiet and well lit. Others might want to use the personal loop system. For those with profound hearing loss, I will often use a laptop linked to another laptop or an iPad. I type what I would normally say and the text appears on the other screen which is in front of my client. The client can speak back to me so they don't have to use the computer."

What needs to happens

The Department of Health, Social Services and Public Safety must introduce a children's mental health assessment service.

Mental health services should adopt a 'whole life' approach, and ensure a smooth transition between children and adult services.

The Department of Health, Social Services and Public Safety should ensure deaf children and young people have access to mental health services that have the understanding, knowledge and skills to meet the needs of deaf children and young people, such as specialist CAMHS service.

⁶⁸ Paddock et al, 2008

⁶⁹ Hidden Lives, Psychological and social impact of becoming deafened in adult life, Link Centre for Deafened People, 2005

The Department of Health, Social Services and Public Safety should ensure deaf children and young people and their families are fully involved in the support they receive and the development of services.

The Department of Health, Social Services and Public Safety should improve the information and data that is available on the mental health and emotional wellbeing of deaf children to ensure the development of services and policies are properly informed and outcomes are monitored.

GPs need to be made aware of the specialist Mental Health and Deafness Service.

Deaf people need to be informed and educated about mental ill health and appropriate services.

Mental health services should be accessible to people with all levels of hearing loss, regardless of their first language.

Generic Mental health workers should be trained in the psychological, sociological and psychiatric aspects of deafness.

Hospital inpatient facilities are required for a small number of clients with more acute mental health problems. Consideration should be given to developing such a facility on an all-Ireland basis.

During an admission period, appropriate and accessible communication support must be provided within a maximum of 24 hours.

All deaf service users should be enabled to give fully informed consent for their treatment, which includes the provision of qualified communication support.

Deaf people should be supported to train as mental health professionals.

The Department of Health, Social Services and Public Safety should provide an effective, holistic rehabilitation process for people with hearing loss, which includes a mental health input.

Dementia and deafness

Research has shown that people with mild hearing loss have nearly twice the chance of going on to develop dementia as people without any hearing loss. The risk increases to threefold for those with moderate hearing loss and fivefold for those with severe hearing loss.⁷⁰

The fact that hearing loss can precede the onset of dementia indicates that early intervention (hearing screening and aural rehabilitation) may be extremely important in terms of minimising the risk and impact of dementia.

Hearing loss, deafness and dementia are often addressed separately. Not only is hearing loss often undiagnosed⁷¹, but hearing loss may be misdiagnosed as dementia⁷² or make the symptoms of dementia appear worse, or dementia may be underdiagnosed because of hearing loss or deafness.

Both hearing loss and dementia need to be addressed early⁷³ and when they are diagnosed and treated they should take into account each other's challenges. There should be a systematic approach to hearing assessment that allows for the high levels of co-occurrence of hearing loss and dementia, and takes into account the challenges around this.

For example, audiological assessments for people with dementia have been developed which simplify instructions and use shorter sentences⁷⁴, and some audiology departments have adapted their testing procedures so that they meet the needs of people with dementia.

People with hearing loss and deaf sign language users should be able to access services that diagnose and help people to manage their dementia as effectively as possible.

People with dementia and unmanaged hearing loss are at a high risk of requiring a high cost intervention at an early stage. Cost savings could therefore be made through better management of hearing loss, providing services that are accessible to people with hearing loss or deafness, and ensuring that the diagnosis and management of dementia takes a person's hearing loss into account. Ensuing reductions in the need for residential care have been estimated to potentially save at least £0.8 million per year

⁷⁰ Lin, FR et al., 2011).

⁷¹ Burkhalter et al., 2009

⁷² Boxtel van et al., 2000

⁷³ Alzheimers Disease International website, 2013

⁷⁴ Lemke, 2011

in Northern Ireland.⁷⁵ Further savings would be made through reducing hospital admissions and the need for specialist care, avoiding delayed or incorrect diagnoses and more effective management and re-ablement⁷⁶.

For sign language users who have dementia, communication must be available in BSL. Where interpreters are required, qualified sign language interpreters must be provided to ensure a proper communication environment. This may be a challenge in some settings, such as care homes. For assessments of language and communication, mediation via an interpreter is not always sufficient. The Alzheimer's Society is currently funding research to design appropriate cognitive assessment tools to diagnose dementia in Deaf people and to build culturally relevant information and support⁷⁷

Case study

A deaf woman who signed was a long-term resident in a residential home. She was not given communication support because her notes explaining her need were lost. Lacking the means of communication, she developed behavioural difficulties and was then misdiagnosed as of low intelligence. She was kept in total isolation for 30 years until the home was closed down and the truth was discovered. She had by then lost her ability to sign. The lack of communication support had led to total isolation and would likely be considered inhuman and degrading treatment.⁷⁸

What needs to happen

Healthcare specialists need to develop better diagnostic tools, specialist services and guidance to support people with hearing loss who also have other long term conditions, and make sure these are used.

It is essential that services address the underdiagnosis of dementia in the presence of hearing loss and deafness.

⁷⁵ Action on Hearing Loss, *Joining Up* 2013

⁷⁶ Action on Hearing Loss, *Joining up* 2013

⁷⁷ Atkinson et al., 2011

⁷⁸ RNID, cited in Daw, R (2005) Human Rights and Disability: the Impact of the Human Rights Act on disabled people, Disability Rights Commission/ RNID

Tinnitus

Tinnitus, often described as 'ringing in the ears', is the perception of sound in the head or ears when no external sound is present. It may be acute or chronic. Acute tinnitus lasts days to weeks while chronic tinnitus is persistent, lasting for longer than six months.⁷⁹

Tinnitus is generally correlated with hearing loss, but the two can exist separately. It can be a constant sound or noise, from which the individual gets no relief, except when asleep, or can occur intermittently for several minutes to hours at a time, before stopping until the next episode.

While up to 275,000 people in Northern Ireland have tinnitus to some degree, at least 7000⁸⁰ people have severe tinnitus, which significantly affects their ability to lead a normal life. Delays in receiving support can lead to increased anxiety and/or depression for the person with tinnitus and in some cases they are unable to work due to the impact of the condition on their daily life.

Research carried out in 2010⁸¹ revealed gaps in the provision of services for people with tinnitus and a lack of information for both professionals and patients on what additional support exists.

There is no clear path for people with tinnitus to follow to get help. Many people are not aware that the noise they are hearing is tinnitus, and that there is help available. GPs are not always equipped with the appropriate knowledge and information to help. Each area in Northern Ireland has a different level of support available, and many people with tinnitus become very distressed and do not know where to turn for help.

The impact of tinnitus on individuals varies and is dependent on a range of factors, such as severity, duration, pre-existing psychological characteristics and so on. An individual's reaction to tinnitus may lead to a state of constant anxiety, directing attention to tinnitus and establishing a 'vicious circle' when tinnitus increases in direct proportion to anxiety.⁸²

Tinnitus is associated with a higher occurrence of depression than in the general population.⁸³ According to Daugherty (2007), at least 40-60% of patients with tinnitus also have a major depressive disorder, which often

^{79 (}Daughterty, 2007).

⁸⁰ What's that Noise?, Action on Hearing Loss, 2010

⁸¹ What's that Noise?, Action on Hearing Loss, 2010

⁸² Ibid.

⁸³ Ibid.

worsens their perception of the condition.⁸⁴ Research⁸⁵ has found that pulsatile tinnitus may have been a risk factor in the deaths of six case studies.

Action on Hearing Loss produced a Tinnitus Strategy for Northern Ireland in 2013, in collaboration with experts in the field from across health, social services, and the voluntary sector. This Strategy has yet to be implemented by the Department of Health, Social Services and Public Safety.

Case studies

"Tinnitus destroys everything you go to do; when you wake up in the morning, it's there; when you go to sleep, it's the last thing you hear. No matter what you do or where you go, it's usually there; it spoils your life."

"One time I remember saying to myself, whenever it was very bad, 'How am I ever going to live with this noise in my head non-stop? I can't go on with life'. I was going to take an overdose, I just couldn't hack it."

"You get down days, you get depressing days, you get days when you don't want to get out of bed, you get days where you don't want to go on living."

What needs to happen

The Department of Health, Social Services and Public Safety should implement the Tinnitus Strategy for Northern Ireland as a matter of urgency.

The Public Health Agency should make the public aware of what tinnitus is, and where to seek help.

The Department of Health, Social Services and Public Safety should provide GPs with specialist information for themselves, and for people with tinnitus and their families.

⁸⁴ Daugherty, J.A. (2007), 'The Latest buzz on Tinnitus', *The Nurse Practitioner*, (32) 10, 42-47.

⁸⁵ Lewis et al (1992)

GPs must be trained to support people with tinnitus and refer appropriately.

Professionals in ENT, Audiology, Social Work and the voluntary sector must work together to provide support for people with tinnitus at the earliest opportunity, and in a way that is appropriate for them.

Health and Social Care Trusts should identify, train and resource a specialist tinnitus professional in each area to provide a specialist tinnitus service.

All tinnitus support services should be joined up and embedded into the patient pathway at every stage of the journey.

GPs and mental health services need to be aware of the mental health impacts of tinnitus, and the need to intervene early.

Everyday Services

Relevant articles

Article 9: Accessibility

Article 20: Personal mobility

Article 25: Health

Article 30 - Participation in cultural life, recreation, leisure and sport

Access to Transport

In the UK legislation requires all new buses and trains to meet minimum accessibility standards including audio-visual information systems on trains. Disabled passengers have additional rights when using transport services and accessing travel information. As part of these rights all public transport services including taxis must carry assistance dogs. Under European Regulations disabled people have rights when travelling by air or by ferry.

Today deaf people have to overcome barriers in using public transport. Inaccessible information, communication difficulties or changes in route presents deaf people with major problems. Research has shown that at least a quarter of respondents found it difficult to obtain information during travel. The survey also revealed that almost half of respondents (45%) would prefer to obtain travel information in person.⁸⁶

There is still no legal requirement for audiovisual information on buses and entertainment systems on aircraft are often inaccessible, with no subtitles or loop systems. In train stations, even where visual information screens are installed, they are often not updated with real time information, such as changes in service or platform.

Technology has advanced in recent years and as a result deaf people are able to access details online, for example, finding out if their train will arrive on time. This of course has reduced frustration but in situations where a route has been altered at the last minute, information is not clearly accessible for deaf people.

Last minute time table or platform changes or unexpected delays are not always communicated to participants. Tannoy systems are not accessible

⁸⁶ Action on Hearing Loss, Need reference for this

and while visual displays went some way to assist communication they are not a fail-safe mechanism.

Case studies

"The bus was going to Portrush and there was a change in Coleraine and I didn't know. So I'm sitting there and I went back to Belfast. I didn't know what was happening"

"I was heading up to university. I thought the train was going to Jordanstown. It actually ended up in Bangor. I got off at Sydenham and walked from Sydenham to Belfast Central."

"They would have had announcements to tell you when to get off the train, such as next stop etc. and I wouldn't have heard what they were saying."

"I have had experiences in England of getting the wrong train because even though there was a visual display it was over-ridden by an announcement and I missed the train."

"When I was going to Dublin and had to get the bus I always had to write the information down because the signs weren't clear enough. I would need better information presented visually so that I could see exactly where I had to go."

Access to Sport and Leisure

Over half of respondents to a survey in 2008⁸⁷ said that accessing leisure centres was difficult or very difficult, while the large majority of the 161 people surveyed expressed an interest in attending.

Conversely, the majority of representatives from leisure centres surveyed said that they had made adjustments to cater for the needs of people with hearing loss, such as the installation of induction loops, staff trained in basic sign language and discounted rates.

Deaf people are also shown to have poorer health outcomes than hearing people, and so it is imperative that access to sport and leisure is made accessible to and inclusive of people with hearing loss, by

⁸⁷ Access to Leisure in NI, Lottery project scoping survey, RNID 2008

a) Improving access to mainstream leisure facilities and sporting activities, by ensuring that: premises have working induction loops fitted at reception; staff are trained in deaf awareness and basic sign language; flashing smoke alarms are fitted; policies and procedures consider the needs of people with hearing loss; information is in plain English; email and SMS access; subtitled TVs in gym areas, etc.

b) Developing activities that are targeted at, and tailored for deaf people, for example, training deaf people to become sports coaches, providing classes taught through the medium of sign language, promotional activities carried out among the deaf community and schools with deaf children.

Case studies

"One time I was at the swimming pool. The staff were setting up the wave machine and didn't tell us to move and we didn't hear the announcements. The waves started and my friend fell and hurt her back."

"I go to a gym that puts subtitles on the TV screen for me when I am working out. It's such a simple thing to do, but they are the only gym I know who does this."

L is a keen horse rider who has a dual sensory loss, and who goes horse riding regularly with a friend who is also deaf. L and her friend do not get any specialist help but their persistence has helped instructors respond to their particular support needs. As a result the instructors now work with them in relays so they receive individual attention and can learn while watching each other.

Participants in the Action on Hearing Loss Healthy Lives project have reported positive outcomes, like Colin who was 16.5 stone when he became involved. He took part in every opportunity - football training, swimming lessons, fitness classes, walking clubs, and tennis. He is now 13 stone and in the elite deaf football squad. He has gained a completely new lease of life.

A 78 year old deaf man attended almost every deaf swimming session. He said he felt really comfortable with a BSL coach and he learned to swim properly for the first time in his life.

Access to TV

Access to the television for people with hearing loss has vastly improved in the last few decades. However, there are still many programmes that remain inaccessible due to a lack of subtitles or signed interpretation, poor quality subtitles or inaudible speech.

Subtitles

In a 2012 survey⁸⁸ on the quality of subtitles, the highest percentage of complaints was in relation to news programmes, with nearly half of respondents experiencing a problem. Entertainment programmes received 18% of complaints and drama programmes received 16%. Around one eighth of respondents complained about subtitles during a sports programme.

62% of problems experienced with subtitles were due to delays. Problems with accuracy were the second most common issue, identified as a problem by 45% of respondents. Over one third of respondents complained about a complete lack of subtitles on the programme they were watching.

We urge all broadcasters to monitor the quality of their subtitling in order to ensure high standards. Technology needs to be further developed in this area in order to reduce mistakes. However, it is also important to raise awareness amongst the public about the current limitations of subtitles to manage expectations.

Video on demand

The way that television is delivered has changed dramatically, yet there is little subtitled TV online and subtitling is lagging behind in high definition (HD) television, internet protocol television (IPTV) and video on demand (VOD).

Progress remains slow as there is no legal requirement to provide subtitling or signing, and as a consequence many service providers continue not to provide these access services.

Content providers need to ensure that the accessibility of VOD services is brought in line with traditional linear broadcasting services, so people with hearing loss have equal access.

⁸⁸ Action on Hearing Loss (2013) Getting the full picture? Viewers' experiences of television subtitling

Quotas for access services should be extended to all television programmes, regardless of how they are broadcast or watched. Clarity of speech and the quality of live subtitling must be improved.

We believe that legislation should be brought in as soon as possible to ensure people with hearing loss have equal access to VOD.

Access to Cinema

People with hearing loss have a limited choice of films at the cinema due to the lack of adjustments made by cinema exhibitors and distributors. People with hearing loss should be able to choose which film they would like to see, as well as the time they would like to see it.

A report to the UK Film Council in 2007⁸⁹ found that only 27% of people who are deaf or hard of hearing attend the cinema at least once a year, compared with 72% of the general population.

If people with hearing loss attended the cinema as often as the general population, this would generate 6.4m annual admissions, or around $\pounds30m$ at box office.⁹⁰

In Northern Ireland only a small number of cinemas provide regular subtitled screenings.

Case study

"Personally, I find that if the loop system is not available and I am not able to hear clearly, I feel like a second class citizen. When working loop systems are available, my wife relaxes because she knows I can hear, and enjoy what is happening, and we can discuss what we went to see because I haven't missed half of what is being said!"

What needs to happens

Transport:

Government should ensure that public transportation is accessible to people are deaf, deafblind, have a hearing loss or tinnitus, by using good practice, such as:

- pre-travel information available in a variety of formats;

⁸⁹ A study of cinema access and film consumption for audiences with sensory impairments: A report for the UK Film Council 2007 ⁹⁰ Action on Hearing Loss, 'Access to the cinema for people with hearing loss' Policy statement

- real time information available using accessible technology, such as realtime audio visual displays;

- Induction loop systems installed, clearly advertised, switched on and regularly tested;

- Accessible complaints procedures;

- consideration of safety issues such as help points designed for people with hearing loss, and the fitting of visual emergency alarms;

- good lighting;

- visual interior warnings should be fitted to inform passengers of stopping and door closures;

- ensure staff making announcements have clear speech;

- Controlling and minimising background noise during announcements.

Cinema:

- An increase in the number of subtitled films shown by cinemas across Northern Ireland;

- Subtitled films shown at more convenient times;

- All loop and infrared systems clearly advertised, maintained and regularly tested and all staff trained in their operation;

- cinemas with infrared systems in their screens should have both neckloops and stereoclips available;

- A variety of ways to find out about cinema listings, including by telephone, textphone, online and in person;

- Use a recognised logo in listings to identify subtitled showings;

- An alternative to the automated telephone system, or an option to speak to a member of staff directly;

- Monitor sound levels to ensure they are not excessively loud

Media:

Broadcasters should reduce background noise on television and radio programmes.

Broadcasters should promote greater involvement of viewers with hearing loss in subtitling and signing programmes, and in creating more audible content.

Subtitling should be available on all programmes, regardless of method of delivery. This includes programmes shown through catch-up, VOD or live streamed TV.

Culture and language

Relevant rights

Article 30 - Participation in cultural life, recreation, leisure and sport

Profoundly deaf people who are members of the 'Deaf community' use either or both British Sign Language (BSL) and Irish Sign Language (ISL) as their first language.

The Deaf community uses the upper case 'D' to signify that they are members of a cultural community, using a shared language and having a shared experience.

It is accepted by the Coalition on Deafness that up to 3000-5000 people in Northern Ireland use sign language to communicate, although the latest data available through the 2011 Northern Ireland Census provides a much lower figure, which may be due to a number of factors.

For the Deaf community English is a second language and services provided through English are often inaccessible. The introduction of the Disability Discrimination Act 1995 has enshrined the right to a 'reasonable adjustment' to the way information on goods, services and facilities is provided, however, specific protection of the rights of sign language users to receiving information in their first language has not been secured.

BSL and ISL received official Government recognition in Northern Ireland in 2004, which led establishment of the Sign Language Partnership Group (SLPG) at the Department of Culture, Arts and Leisure, and associated grant funding for projects to promote the languages.

However, to protect sign language and to further secure the rights of BSL / ISL users to access services in their first language, further legislation is required.

Case study

Language acquisition is an early specific neurological developmental task and twentieth century educational policies that deaf children must not learn language visually through sign, but only through the 'oral' method (speaking and lip reading) have often resulted in serious language delays and deprivation. Deaf people have often only learnt to sign covertly at school from Deaf children from Deaf families, or later in life when they join the Deaf community. It therefore cannot be assumed that a Deaf person has fluent sign language. Poor education can also mean that a Deaf person's written English is limited or in sign word order. ⁹¹

What needs to happen

Government needs to:

- Identify the numbers, location, age, gender and socio-economic position of sign language users in Northern Ireland;

- Ensure equal access to public services to sign language users;

- Explore the benefits of a bilingual approach to teaching Deaf children who use sign language;

- Improve social and personal development opportunities for Deaf people who use sign language as their first language

- Promote sign language as a viable and celebrated means of communication in Northern Ireland

⁹¹ Dr Margaret de Feu, 'Irish Psychiatrist' 2009

Relevant rights

Article 9: Accessibility

Sign language interpreters and teachers

In 2008 the Department of Employment and Learning committed £1.3million to the training of sign language interpreters and deaf tutors, with the aim of creating a sustainable infrastructure for Northern Ireland to ensure supply matched demand in future, to the highest standard possible.

A new qualification was created to enable interpreting students to achieve a Masters level qualification in sign language interpreting for the first time. A one year progression course was established at Belfast Metropolitan College to feed students onwards to Queens University to complete the MA in Translation.

The first year was treated as a pilot, with the majority of students being already qualified to at least trainee level, and practising in the field, before the course commenced.

Alongside this, the training of deaf people as sign language teachers is ongoing through Ulster University, following on from a progression course delivered by Belfast Metropolitan College. This course provides qualifications in English, sign language and teaching. The aim is to increase the range of sign language courses available to the public, to create a supply of interpreters for the future, and create sustainable employment for deaf people.

A delay in establishing the training of deaf tutors has meant that currently there are no teachers to teach Level 3 sign language and above to potential interpreters, meaning that progression onto the Masters has been halted.

As before, student interpreters are left with no choice but to study outside Northern Ireland for at least part of their progression to qualified status and at their own expense.

Communicator Guides

The largest group of deafblind people, people with an acquired dual sensory loss, will still use speech to communicate, and require professionals to use best practice when communicating with them.

Other deafblind people communicate using a variety of adapted and special methods. For healthcare appointments for example, most need the services of a Language Service Professional (LSP), who has skills in sign language, the Deafblind Manual Alphabet, lipspeaking or speech to text methods.

Communicator guides are LSPs who are trained to support deafblind people with communication and mobility, to enable their involvement in everyday activities and alleviate isolation.

However, over three-quarters of deafblind people rely on friends and family to provide communication and guiding support for medical appointments⁹².

There is only one registered Communicator Guide in Northern Ireland.

Case Study

A 79 year old blind woman uses a hearing aid to support her deteriorating hearing, she lives independently and copes well at home in a familiar environment. However, outside the home she was experiencing increasing difficulty.

She could no longer get the bus to the shops as she could not see the bus numbers and relies on other people to tell her which bus has arrived. However, due to the background noise of traffic, she can't hear what people are saying and has felt confused and unable to travel. As well as shopping for food, her weekly trip is a vital link to the ethnic community where she is known. Because of this she is reluctant to use a shopping service.

A one-to-one communicator guide provided at this stage will ensure her continued involvement in these activities, enable her to make independent choices and help prevent further deterioration in her physical and mental health. Without this, she is at risk of losing skills and requiring higher levels of care, including the possibility of needing residential care.

⁹² Deafblind UK Cause and Cure, 2006

Quality standards

Access to goods, services, facilities, transport, education and employment is a requirement of the Disability Discrimination Act 1995 and the Disability Discrimination Order NI 2006. The UNCRPD supports the right to equality of communication and language.

To ensure quality of service and the safety of the person using it, when communicating with deaf sign language users and deafblind people service providers should source communication and language professionals who

- meet the national occupational standards for their profession;
- have professional indemnity insurance; and
- hold a current Access NI certificate.

Where possible, communication and language professionals should also be on a register, such as those held by NRCPD. Such registration provides additional public protection as Registrants are

- held accountable to a Code of Conduct;
- obliged to update their skills through compulsory continuing professional development;
- asked to make a fit and proper persons declaration; and
- asked to confirmed they hold an up to date criminal record disclosure

Case study

"They asked me to interpret for my Dad and I said I would but only if there were no interpreters available. For all the scans, blood tests and the chemotherapy that followed they never ever booked an interpreter for him again.....The cancer was getting worse. The consultant used lots of medical terms but all I translated was 'it is getting worse'. She used more medical words to describe the situation but I could only translate it as: 'there is no point continuing with the chemotherapy – you will get very ill.' I look back on this experience and feel as though I was a forced volunteer. I was there to be my dad's support, not his interpreter. I fear that other families like ours will have to suffer the same experience if things don't change."⁹³

⁹³, <u>http://limpingchicken.com/2013/04/23/i-told-dad-his-battle-with-cancer-was-lost-because-the-nhs-didnt-provide-an-interpreter/</u>

What needs to happens

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.

Government should conduct an analysis of capacity and demand for sign language interpreters, in the context of best practice in other parts of Europe.

Services should recognise the right of a deafblind person to have appropriate support.

Public services should ensure that all interpreters and deafblind communicators booked through agencies are registered with a professional body such as the NRCPD (National Register of Communication Professionals working with Deaf and Deafblind People).

Quality assurance procedures should be put in place to ensure communication support professionals are registered, for example, by quoting the NRCPD registration number of the communication professional used when claiming payment.

Public services must provide qualified communication professionals when communicating with Deaf sign language users and deafblind people.

Public services should apply quality standards in the procurement of language professionals.

Public services should carry out regular compliance checks of language professionals they employ.

Government needs to invest in the training of more Communicator Guides for deafblind people.

Relevant rights

Article 9: Accessibility

Loop and infrared systems have improved access to private services, but even where a loop system is installed it is often switched off, not tested or poorly maintained, and staff are frequently unaware of its existence. In 2010 a survey⁹⁴ found that 81% of over 50 shops and services in Belfast were inaccessible to people using hearing aids. Of the 26 premises that did have a loop system, only 10 were fully functioning.

This means that people with hearing loss continue to struggle with communication in public places completely unnecessarily. There are a number of technologies available for businesses and other organisations that want to be fully accessible to customers and staff with hearing loss, including TalkByText, TextRelay, and Video Relay services.

However, businesses and service providers are increasingly using call centres which are not compatible with these technologies, making them inaccessible to people with hearing loss.

Case study

'Let's Loop Eastbourne' – a Hearing Link campaign to transform Eastbourne, East Sussex, into an example of good hearing loop practice

The campaign used volunteers to check loop systems assessing signage, sound quality and positioning of the hearing loops. Positive and negative feedback was provided to businesses who were encouraged to address problems where they existed. The campaign also raised the profile of loops amongst hearing aid users, many of whom were uncertain as to their use.

As a result, loop provision in Eastbourne has improved markedly, awareness has been raised, and examples of good practice shared in the locality. All these results help to increase the confidence and social inclusion of hearing aid users.

⁹⁴ Belfast Loop Blitz, RNID, 2010

What needs to happen

Service providers need to install and clearly advertise a hearing loop or infrared system, and ensure it is switched on, regularly tested and maintained annually.

Service providers should provide a separate telephone number to allow direct access to an operator, or to offer the option to speak to someone at each menu level of an automated call. Where the customer does not respond, these calls should automatically be diverted to an operator.

Article 3: General principles

The principles of the present Convention shall be:

(h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Article 4: General obligations

1. States Parties undertake to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

(a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention.

Article 7: Children with disabilities

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right.

Article 8: Awareness-raising

1. States Parties undertake to adopt immediate, effective and appropriate measures:

a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;

b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;

c) To promote awareness of the capabilities and contributions of persons with disabilities.

2. Initiating and maintaining effective public awareness campaigns designed:

I. To nurture receptiveness to the rights of persons with disabilities;

II. To promote positive perceptions and greater social awareness towards persons with disabilities;

Article 9: Accessibility

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;Information, communications and other services, including electronic services and emergency services.

- 2. States Parties shall also take appropriate measures to:
- a) Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
- b) Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
- c) Provide training for stakeholders on accessibility issues facing persons with disabilities;
- d) Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;

- e) Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;
- f) Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;
- g) Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
- h) Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

Article 20: Personal mobility

States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

- a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
- b) Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;
- c) Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;
- d) Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities

Article 24: Education

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning directed to:

The full development of human potential and sense of dignity and selfworth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;

The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;

Enabling persons with disabilities to participate effectively in a free society.

2. In realising this right, States Parties shall ensure that:

Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

Reasonable accommodation of the individual's requirements is provided;

Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:

Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;

Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;

Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

Article 25: Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- c) Provide these health services as close as possible to people's own communities, including in rural areas;
- d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Article 26: Habilitation and rehabilitation

States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organise, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;

b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

Article 27: Work and Employment

1. States Parties recognise the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;

 e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;

Article 30: Participation in cultural life, recreation, leisure and sport

1. States Parties recognise the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:

- a) Enjoy access to cultural materials in accessible formats;
- b) Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats;
- c) Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance

4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

Article 31: Statistics and data collection

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:

a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;

b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Communicator Guides

Communicator Guides for deafblind people use manual communication to enable deafblind people to understand, participate and interact. The interpreter will also relay visual and other non-verbal information, for example reactions to what has been said, movement of other people and what they are doing.

Lipspeaker

Lipspeakers repeat spoken messages for people who can lipread. They can be used to ensure clear communication in critical situations, or in situations where there is more than one voice to follow. Lipspeakers use facial expression, natural gesture and fingerspelling to support communication.

Notetaker

Notetakers produce an accurate summary record of speech, which a deaf person may use for reference.

Sign language interpreter

Sign language interpreters transfer meaning from one spoken or signed language into another signed or spoken language. Interpreters will use their skill and knowledge of the two languages, and their understanding cultural differences between those for whom they are interpreting, to transfer a message in one language into the other language.

Sign language translator

Sign language translators translate written text from one language into another. Most often this will be written English into a signed language for the purposes of broadcasting or web access.

Speech to text reporter

Speech to text reporters take words that are said and use a phonetic keyboard to show them instantly on a monitor or screen. They provide a complete transcription of spoken words and include notes of environmental sounds, like laughter and applause.

Contact details

Action Deaf Youth

Office 16 Townsend Enterprise Park 28 Townsend Street BELFAST BT13 2ES Website: www.actiondeafyouth.org

Action Deaf Youth is a deaf youth organisation in Northern Ireland delivering youth, employment, transitions and training support. Youth Support provision is provided in different regions across Northern Ireland which enables deaf children and young people aged 4 to 25, to fulfil their potential and pursue new opportunities.

Personal development, employability and sign language training programmes are on offer for deaf young people aged 13 onwards.

As well as providing support, the organisation has a Deaf Youth Advisors Forum - a group of deaf young people aged 16-25 who currently work to advocate, campaign and to address current needs of deaf children and young people.

Action on Hearing Loss

Harvester House 4-8 Adelaide St Belfast BT2 8GA Tel: 028 9023 9619 Text: 028 9024 9462 Email: <u>information.nireland@hearingloss.org.uk</u> Website: <u>www.actiononhearingloss.org.uk</u>

Action on Hearing Loss is the charity working for a world where hearing loss, deafness and tinnitus don't limit or label people, and where people value their hearing.

If you need to book communication support for service users please contact 028 9033 1320 or email <u>csubelfast@hearingloss.org.uk</u>

If you need equipment, such as induction loops, you can find our huge range of products here: <u>www.actiononhearingloss.org.uk/shop</u>

If you need a technician to install your equipment, further information is available at: www.actiononhearingloss.org.uk/supporting-you/products-and-equipment/how-to-make-your-service-accessible/product-installation

Action on Hearing Loss provides a consultation service and best practice charter mark, Louder Than Words®, to help you become fully accessible to people with a hearing loss. More information is available here: www.actiononhearingloss.org.uk/louder-than-words

Deafblind UK

P.O. Box 359 Bangor Co. Down BT20 9EW Email: norman.mccudden@deafblind.org.uk Website: www.deafblind.org.uk

The Deafblind NI 'Connections NI' project is working with older people who are coping with a dual sensory impairment, i.e. a level of hearing loss <u>and</u> a level of sight loss, to provide peer support, local advocacy and befriending.

Peer Support Groups are now running in Belfast, Newtownabbey, Coleraine, Craigavon, Downpatrick and Newry.

Our volunteer befriending service aims to reduce social isolation and loneliness experienced by Deafblind members with dual sensory loss.

Deafblind NI is also introducing its members to the benefits of new digital technology to assist them with their day to day activities and needs.

Connections NI accepts referrals via Social Services teams, other organisations working in the voluntary sector and directly from individuals, their friends and family.

Hearing Link Northern Ireland

23 Enterprise House Lisburn Enterprise Centre Lisburn BT28 2BP Tel/text: 07534 563451 Email: <u>northernireland@hearinglink.org</u> Helpdesk: <u>enquiries@hearinglink.org</u> Website: <u>www.hearinglink.org</u> Hearing Link is a UK charity that provides information and support to people with hearing loss, their family and friends and focuses on those who communicate by listening, lipreading and text-transcription. Hearing Link is a friendly and knowledgeable organisation and a great point of contact for anyone who is adjusting to hearing loss or managing the challenges that it can bring.

Hearing Link is now offering specialised rehabilitation and selfmanagement programmes in Northern Ireland. Information on these programmes is available via the contact details above

National Deaf Children's Society

38-42 Hill Street Belfast BT1 2LB Tel: 028 9031 3170 (v) Fax: 028 9027 8205 Text: 028 9027 8177 Website: <u>www.ndcs.org.uk</u>

NDCS is the leading charity dedicated to creating a world without barriers for deaf children and young people. We help deaf children thrive by providing impartial, practical and emotional support to them and their families, and by challenging governments and society to meet their needs. In Northern Ireland we offer a family officer, events, campaigns and emotional health and wellbeing services among others. NDCS believes that every deaf child should be valued and included by society and have the same opportunities as any other child.

Northern Ireland Deaf Sports

c/o Harvester House 4-8 Adelaide Street Belfast BT2 8GA Email: <u>info@nideafsports.org</u> Web: <u>www.nideafsports.org</u>

Northern Ireland Deaf Sports is the governing body for Deaf Sports in Northern Ireland. Its work includes the development and promotion of deaf sports, supporting local deaf sports clubs and societies in organising local and national competitions and championships and providing opportunities for deaf people to take part in open competitions with other deaf persons from outside the country.

Sense, The National Deafblind and Rubella Association

NI Regional Office The Manor House 51 Mallusk Road Mallusk BT36 4RU Tel: 028 9083 3430 Fax: 028 9084 4232 Text: 028 9083 3430 Email: <u>nienquiries@sense.org.uk</u> Website: www.sense.org.uk

Sense is a national charity that supports and campaigns for children and adults who are deafblind.

We provide tailored support, advice and information as well as specialist services to all deafblind people, their families, carers and the professionals who work with them. We also support people who have a single- sensory impairment with additional needs.

We believe that every deafblind person has the right to choose the support and lifestyle that is right for them; one that takes into account their longterm hopes and aspirations.

Our specialist services enable deafblind people to live as independently as possible, offering a range of housing, educational and leisure opportunities.

Signature

Mersey House Mandale Business Park Belmont Durham DH1 1TH Website: www.signature.org.uk

We are a national charity which campaigns to improve the standards of communication with deaf and deafblind people in the UK. Our vision is of a fully accessible society, powered by a greater understanding of the languages and communication methods used by deaf and deafblind people.

A leading authority in the sector, we have more than 30 years' experience in advising government and business; publishing educational resources; campaigning and lobbying. Our work remains as important to us now as it was on the day the charity was established.

We are widely respected as the leading awarding body for nationally recognised qualifications in British Sign Language and other deaf communications. You can study our qualifications at around 500 locations across the UK, from beginner level to professional level.

