



The *Care Cameos* series is designed to present short but challenging sketches of various issues and to provide a forum to encourage and foster debate on a whole range of issues important for the delivering of care and support for older individuals across Scotland.

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CARING ABOUT COMMUNICATION: WORKING BETTER WITH PEOPLE AFFECTED BY DEAFNESS

A CARE CAMEO

NOVEMBER 2018

Preface

Welcome to the eighth of Scottish Care's *Care Cameos*.

The *Care Cameos* series is designed to present short but we hope challenging sketches of various issues and to provide a forum to encourage and foster debate on a whole range of issues important for the delivering of care and support for older individuals across Scotland.



I am delighted that this Cameo has been written and developed by Janis Macdonald, the Chief Officer of deafscotland alongside her colleagues, Carolyn Scott and Mandy Reid. It focusses on the critical issues of communication and human rights as they impact upon the deaf community who access social care supports and services, and who increasingly work in them.

Communication lies at the heart of what it means to relate to another human being. It is the bridge which links two lives in a relationship, it is the energy which reaches beyond the self to another, and it is the strength which unites otherwise divided communities and nations. This work rightly argues that communication should be considered as a human right and as such should be given as equal priority and resource as any other human right in society.

This *Care Cameo* asks some challenging questions and makes some significant recommendations. In a social care context where resource is limited and stretched it is critically important that we do not simply settle for the maintenance of what we have but strive to improve and enhance the dignity and rights of others. It is critical that we begin to hear the voices of those who have a right to be heard and that we learn the communication skills which will enable us all to live in that togetherness which true communication fosters and nurtures.

Martin Luther King once said that:

"People fail to get along because they fear each other; they fear each other because they don't know each other; they don't know each other because they have not communicated with each other."

Communication enables the abandonment of fear and the creation of community; inclusive communication enables those who have been silenced by structures and systems to find the means to be heard and to have their contribution recognised. Care at its best enables those who are supported and cared for to have their right to be heard come alive.

I hope you enjoy this Cameo.

Dr Donald Macaskill
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About this Care Cameo



This *Care Cameo* has been written by Janis McDonald, the Chief Officer of deafscotland, with support from colleagues Carolyn Scott and Mandy Reid (Consultant).

Deafscotland (previously the Scottish Council on Deafness) is the lead organisation for deaf issues in Scotland. They aim to ensure that deaf people in Scotland can access services and information across all sectors of society

from their local communities to what comes from government departments.

Introduction

deafscotland's fundamental goal is for a society where deaf people have equal access, rights and citizenship. Unfortunately, this is not the society we live in today, but it could be.

Preparing this paper made me think about the fundamental aspects of care: the value base, quality, involvement and empowerment. Aware of the spectrum of care needs and the range of ages involved, the paper reflects that the majority of those with hearing loss are over 40 years of age and, significantly, that older adults often face dual sensory loss as hearing and vision deteriorate.

The paper covers a range of relevant issues but can only ever be a provocation and a starting point for organisations and their staff teams to develop a deeper understanding of deafness, communications and the impact of hearing loss.

At deafscotland we are working hard to express our approach in the context of human rights recognising that language and communication are rights and also enablers to rights. Always remember that sensory deprivation is a form of torture. In that light we believe wholeheartedly that more attention is needed to address the barriers faced by deaf people and that we need to shift mainstream communication. A huge task in terms of culture change.

This paper aims to give an overview of the diversity of deafness and the reality of deafness in Scotland today. It seeks to highlight that being able to communicate effectively underpins almost every aspect of our lives. In order to live in society we must be able to interact with other members of that society. Communication is the primary means by which people affect one and other. It makes us human.

As we consider how to create an equal society we do so by acknowledging communication as a human right and, by framing that within the social model of disability, show how society could - and

should - change to enable rather than restrict deaf people.

It is societal barriers and prejudices that disable those within the four pillars of deafness. By understanding the diversity of deafness within the context of the social model of disability we can work to create a society that works for everyone.

The Reality of Deafness in Scotland

- In Scotland around 1,012,000 people have some degree of hearing loss, of whom approximately 546,000 are over the age of 60.
- In the 2011 Census 350,492 of the Scottish population aged 3 and over listed deafness or partial hearing loss as a long-term health condition.
- There are an estimated 57,000 people with severe to profound deafness.

Respecting the human right to communicate of deaf / deaf Sign Language users (approximately 12,500), deafened (up to 350,000), deafblind (approximately 4,000) and hard of hearing (approximately 600,000) people remains a significant problem in Scotland. Consequently, institutional and systemic failures lead to everyday breaches of other human rights of deaf / deaf Sign Language users, deafened, deafblind and hard of hearing people.

A 'one size fits all' approach ignores the variety of communication needs of the one million including filtering and translating information.

Deaf / deaf Sign Language users, deafened, deafblind and hard of hearing people have the right to access information in a format and manner which makes it accessible and purposeful, and this must be received in a timeframe which makes it useful.

Defining Deafness - Four pillars of deafness

As with any sensory impairment, and indeed any disability, every deaf individual is unique. Whether deafness has occurred later in life, or been determined at birth, whether it is profound or a hardness of hearing, deaf people interact with the world around them in different ways.

When we use the term deaf, we mean it to include people on the full spectrum of deafness. We define the diversity of deafness using the 'four pillars of deafness': deaf Sign Language users, deafblind, deafened and hard of hearing people.

What do these terms mean?

Deaf Sign Language users

Deaf Sign Language users are people whose first or preferred language is British Sign Language (BSL), or another Sign Language if they grew up in another country. These people have been born deaf or have become deaf early in life. People with this level of deafness are described as being profoundly deaf. Deaf BSL users usually see themselves as part of a linguistic/cultural minority known as the Deaf Community. A hearing professional who is not proficient in BSL (equivalent of BSL Level 3) must book a BSL/English Interpreter for all meetings and appointments with a Deaf Sign Language user in order to communicate effectively with the person.

Understanding: Imagine you have just landed in a foreign country. You do not speak the language, and nobody in that country speaks English. Imagine the impact that has on you. Would you become fearful? Would you be able to act with the same independence you have at home? Would you become isolated?

People who are deafblind

Deafblindness is sometimes called dual sensory impairment. This is because deafblind people will have both some hearing loss and some sight loss. A person can be born deafblind (called congenital

deafblindness) or lose both their hearing and sight in later life. Some people who are born with deafblindness may also have physical and/or learning disabilities. A person who is born deaf who later loses their sight is most likely to be a BSL user. Other deafblind people may be born blind and lose their hearing in later life. These people will use a spoken language and may also use braille for written documents. Some deafblind people have a condition called Usher Syndrome.

It is important to remember that many deafblind people may not be totally deaf nor totally blind. Professionals should always find out exactly what form of language and/or communication support the person needs. It could be the person needs a Guide/Communicator or has to have written information in Braille. The person may need a BSL/English Interpreter who can use tactile BSL ("hands-on" BSL). The person may have more complex support needs that will need to be addressed.

Understanding: Understanding life for a deafblind person is best reached through simulating their experiences. The use of SimSpecs (spectacles which are altered to give the experience of various vision impairments) to mimic various visual impairments and ear defenders to simulate hearing loss or deafness can be very effective in allowing a person to understand how deafblind people communicate. Imagine you have limited/no sight and limited/no hearing, all of a sudden the physical and tactile environment around you becomes much more important. Touching and feeling become important aspects of how you communicate. How do you interpret someone tapping you on the shoulder? Are they trying to communicate with you? How would you go about communicating with others?

People who are deafened

People who were born able to hear and become severely deaf after learning to speak are often described as deafened or as having an acquired profound hearing loss (APHL). This hearing loss may be due to a disease or illness or there may not be an identified reason for the loss of the person's hearing. Deafened people may rely on lipreading to follow a conversation or need to have things written down for them. If arranging a meeting or appointment with a person who is deafened, it is important to find out what support they need,

for example, an Electronic Notetaker or a Lip Speaker.

Understanding: You are speaking to someone, taking in every word they are saying but then they turn the opposite way and you can no longer hear anything they are saying. Hearing people may experience this in loud environments or windy conditions but imagine that every conversation you have is like this.

People who are hard of hearing

Hard of hearing is a term used to describe people with a mild to moderate hearing loss. People who are hard of hearing will, in general, lose their hearing gradually and the majority of hard of hearing people do so later in their lives. A person with a mild hearing loss might wear a hearing aid and have some difficulty in following conversations in noisy situations. A person with a moderate hearing loss might have one or two hearing aids and will have difficulty following normal speech without the aid. If the person coming to a meeting or appointment uses a hearing aid, then a loop system will enable them to take part. The person may need to use an Electronic Notetaker depending on the nature of the meeting/appointment.

Understanding: You are at a comedy show, engrossed in the comedian's stories, but the microphone keeps cutting out and occasional words are being dropped. The people in the front row are laughing heartily, but you have missed the joke. This continues throughout the performance. How frustrated do you become?

Coming to terms with hearing loss

For people who are deafened or hard of hearing we must understand the role that grief plays. It may take a person some time to realise the extent of their hearing loss, and a lack of screening services or a resistance to access these services due to the stigma attached to hearing aids can compound the sense of grief that comes with hearing loss.

Of course, people do not always easily fit any criteria and those affected by deafness can also have other long-term health conditions to manage or even very complex needs. The pillars describe generalities or commonalities and also indicate that different barriers

require different solutions.

People with hearing loss can be clients of services, relatives and friends of clients and increasingly can be staff members too.

Communication

How do we define communication? We communicate using all of our senses, through sound, touch, sight and even taste and smell. A lack of access to communication is the main barrier deafness creates.

Important characteristics of communication:

- Communication is dynamic - it is in a constant state of change.
- Communication is continuous - it never stops; even as we sleep our brain is active and processing information through our dreams.
- Communication is irreversible - once a message is sent it cannot be undone.
- Communication is interactive - it exists as a relationship between people.
- Communication is contextual - it forms part of our entire human experience.¹

Being able to communicate effectively underpins almost every aspect of our lives, from daily tasks such as shopping and personal welfare, to education, employment, entertainment and democratic participation. In order to live in society we must be able to interact with other members of that society as communication is the primary means by which people affect one and other².

If we cannot communicate effectively we cannot participate fully in

¹ Roy Berko, Andrew Wolvin & Darlyn Wolvin, *Communicating*, Houghton Mifflin Company, Boston, New York, 2001, p.4

² Social psychological models of interpersonal communication, Robert M. Krauss & Susan R. Fussell In E. E. Higgins & A. Kruglanski (eds.), *Social Psychology: Handbook of Basic Principles*. Guilford. pp. 655--701 (1996)

everyday life. Communication creates a relationship, one that seeks understanding. As such, it must be a process in which all participants have the tools they need to achieve understanding.

When we communicate we create the relationship of sender and receiver, but it is important to note that in meaningful interpersonal communication those roles are fluid and move between each individual. Listening and seeking understanding are vital to meaningful communication.

When interacting with people with any kind of sensory impairment, communication should be as inclusive as possible. Inclusive communication is communication that does not discriminate, so that all participants are aware of what is going on around them. It covers all ways of communication whether it is face to face, on the telephone, online, in print or on signs and posters. Inclusive communication recognises that we have many ways of understanding and expressing ourselves.

The importance of inclusive communication in creating a cohesive and equal society cannot be understated; communication is a right not a privilege.

A Human Rights Based Approach

If communication is considered to be a fundamental human right not a privilege, then it is important to understand the legislative framework within which this sits. This was first expressed at an international level in Article 19 of the Universal Declaration of Human Rights³ :

Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.⁴

³ McEwin & Santow, 2018

⁴ United Nations, 1948

Article 19 must exist for all people equally, not just for those who are able to communicate effectively within the current societal structures. Article 19 must be attainable for those within the four pillars of deafness.

In order for equality and inclusion to exist we must not just recognise that communication is a basic human right, but also understand that inclusive communication is vital to allow for the enjoyment of all other human rights.

The human rights that refer to communication and discrimination are:

- The right not to be subjected to torture, inhuman or degrading treatment or punishment (Article 3)
- The right to respect for private and family life, home and correspondence (Article 8)
- The right to freedom of thought, conscience and religion (Article 9)
- The right to freedom of expression and to receive and impart information (Article 10)
- The right to assembly and to associate with others, including in organisations like trade unions (Article 11)
- The right not to be discriminated against (Article 14)
- The right to education, including respect for the religious and philosophical convictions of parents (Protocol 1, Article 2)

Despite the Human Rights Act 1998 and the Scotland Act 1998 requiring government, the public sector and those delivering services of a public nature to comply with the European Convention on Human Rights (ECHR) and other international laws, there has been insufficient progress on compliance with duties and enabling people to assert their rights.

There have been a variety of specific initiatives such as the Scottish Government's Delivery Plan⁵ for the UN Convention on the Rights of Persons with Disabilities and establishing the Scottish Children's Rights Implementation Monitoring Group (SCRIMG) to map progress

⁵ Scottish Government, 2018

and identify actions on the implementation of the UN Convention on the Rights of the Child (UNCRC).

The Scottish Government also set up the Scottish Human Rights Commission which promotes and protects human rights for everyone in Scotland. However, the Scottish Government now wants to see much more impact on rights respected, and duties fulfilled. Key to that is the acceptance of inclusive communication as a right.

Unlike equality laws, human rights law focuses on defining individual rights which must be enjoyed equally by all people. Consequently, government, public bodies and those delivering services of a public nature must comply with the individual rights listed in the ECHR which necessitates different actions to enable equality of outcome.

When the ECHR was drafted in 1950, the definition of discrimination cited some examples but was not restrictive, so that all forms of discrimination would be captured by its provisions. Discriminating against people who are Deaf/Deaf Sign Language users, Deafened, Deafblind and Hard of hearing is a breach of human rights law.

Unfortunately, whether knowingly or not, Scotland's government and public bodies regularly breach human rights law by failing to ensure that people have the right to communicate in ways that make sense to them and to have information that they understand.

The spotlight is increasingly on duty bearers' compliance and their understanding of their obligations so in order that Scotland can fulfil its repeated commitments to comply with domestic and international human rights law and to use human rights to make Scotland fairer.

Tools have been developed for public bodies to avoid breaches: the Scottish Human Rights Commission and the Equality and Human Rights Commission Scotland enable informed decision making via an Equality and Human Rights Impact Assessment, and guidance on using the PANEL principles is available, rooted in the existing law. Evidently, there is no shortage of tools, what does seem to be a problem is the failure to use them and that is now increasingly being

addressed by politicians requiring action from those in leadership and management roles.

The Social Security (Scotland) Bill has as one of its principles '*social security is itself a human right and essential to the realisation of other human rights*'; that '*Scottish Ministers must have regard to the importance of communicating in an inclusive way*'; and '*Scottish Ministers must have regard to the importance of providing information in a way that is accessible for individuals who have a sensory, physical or mental disability*'. Therefore, inclusive communication is now rooted in law and the obligation on duty bearers must be recognised as going beyond social security.

Enabling integration through inclusive communication is a mainstream issue, not a marginal issue, but policy, service and funding decisions in Scotland marginalise and discriminate because the human rights dimension within this is generally ignored. Whilst the British Sign Language (BSL) (Scotland) Act 2015 and the BSL National Plan are very welcome, it increases access to quality communication for only one relatively small group of people across the spectrum of deafness.

Communication is the “enabler” or driver, and the glue in delivering the human rights principles of fairness, respect, equality, dignity and autonomy across our social, economic, civil, political, cultural and environmental rights.

Human rights compliance is required under the Human Rights Act 1998 and the Scotland Act 1998. As the UK has ratified international human rights treaties, all our laws and policies should comply with them and there are several which include the right to communicate in a language which the person understands, such as:

- Adults with Incapacity (Scotland) Act 2000
- Mental Health (Care and Treatment) (Scotland) Act 2003
- Education (Additional Support for Learning) (Scotland) Act 2003
- Gaelic Language (Scotland) Act 2005
- Adult Support and Protection (Scotland) Act 2007
- Patient Rights (Scotland) Act 2011

- Children and Young People (Scotland) Act 2014
- British Sign Language (Scotland) Act 2015
- Carers (Scotland) Act 2016

Understanding the diversity of deafness, we must recognise that the language and communication support needs of deaf people across the four pillars of deafness are all different, yet some of the barriers that people face may be the same.

The hearing world does not always recognise that there are differences in linguistic access depending on the level of deafness the person has and when they lost their hearing. This means that deaf people's access to their rights is breached in different ways.

Thus far, the limited strategy work that has been done nationally and locally on inclusive communication has not properly addressed the human rights implications and it is now appropriate to re-focus and understand the nature and extent of the obligations under human rights law. The future system needs to consider language and communication barriers to be effective, efficient and accessible. A defence of omission is no longer acceptable.

People whose first language is not English can use "race" as the protected characteristic in the Equality Act 2010 to access information and services in their own language. Deaf and deafblind British Sign Language (BSL) users were the only people in Scotland who had to use disability legislation to access information and services in their own language. This basic breach of their human right led to the British Sign Language (Scotland) Act which passed through the Scottish Parliamentary process as a Private Member's Bill and was given Royal Assent in October 2015.

Deaf and deafblind BSL users see themselves as in a linguistic minority rather than disabled. The BSL (Scotland) Act 2015 will take time to make a difference to the lives of deaf and deafblind BSL users so the Equality Act 2010 will remain the main legislation of change at the present time.

The Equality Act 2010

The Equality Act 2010 legally protects people from discrimination in the workplace and in wider society. It replaced previous anti-discrimination laws with a single Act, making the law easier to understand and strengthening protection in some situations. It sets out the different ways in which it is unlawful to treat someone. Before the Act came into force there were several pieces of legislation to cover discrimination, including:

- Sex Discrimination Act 1975
- Race Relations Act 1976
- Disability Discrimination Act 1995

The public sector Equality Duty came into force across Great Britain on 5 April 2011. It means that public bodies have to consider all individuals when carrying out their day-to-day work – in shaping policy, in delivering services and in relation to their own employees.

It also requires that public bodies:

- have due regard to the need to eliminate discrimination;
- advance equality of opportunity; and,
- foster good relations between different people when carrying out their activities.

But the Equality Act does not only apply to public sector bodies, organisations and agencies; it also applies to all service providers and those providing goods and facilities in Great Britain. This includes, for example, those providing information, advice and day care or running leisure centre facilities. It applies to all services, whether or not a charge is made for them. It also applies to private clubs and other associations with 25 or more members which have rules about membership and selection of members

The Act protects anyone who has, or has had, a disability. For example, if a person has had a mental health condition in the past that met the Act's definition of disability and is harassed because of this, that would be unlawful. The Act also protects people from

being discriminated against and harassed because of a disability they do not personally have. For example, it protects people who are mistakenly perceived to be disabled. It also protects a person from being treated less favourably because they are linked or associated with a disabled person.

In reality this has implications for a huge range of matters on a daily basis: the plethora of door entry systems that only sound and do not have lights or visual aids; white goods that only beep and have no flashing lights; telephone only systems for ordering, access or process in the sale of goods and services; sound only fire alarms, and so on.

How does the Equality Act 2010 apply to deaf people in Scotland?

Service providers are required to make changes, where needed, to improve services for deaf people. There is a legal requirement to make reasonable changes to the way things are done. For example:

- Changing a policy to include reducing barriers for deaf people in meetings.
- Making changes to the built environment, such as putting in an induction loop system or a video door entry system.
- Providing auxiliary aids and services such as providing information on DVD with captions and BSL interpretation; providing appropriate professional registered language/ communication support; or, providing additional staff support when using a service.

Reasonable changes are required wherever deaf customers or potential customers would otherwise be at a substantial disadvantage compared with hearing people. A substantial disadvantage is more than a minor or trivial disadvantage. Service providers cannot charge deaf customers for reasonable adjustments. So for example, most hotels are breaching this when not supplying hearing loops in the events spaces. This should apply in care settings too.

Equality is possible

The human rights of those within the four pillars of deafness can be upheld, and meaningful and inclusive communication can be achieved. If we understand deafness within the social model of disability we understand that we can re-organise society to allow for those on every part of the spectrum of deafness to fully realise their human rights. The principles for access and participation are the same across “disability”. Deafness is often referred to as the hidden disability because society does not seem to place the same emphasis on communication that it does for say nutrition, cleanliness or security.

Social Model of Disability

The medical model of disability defines a person’s disability by the limitations of or impairments to their body. The disability is seen as the individual’s misfortune; something to be fixed or remedied, if at all possible, by medical procedures or technology. The social model defines a person’s disability by the limitations of society. The individual is regarded as disabled because society does not have the appropriate infrastructure, procedures, awareness or understanding: society itself disables the individual.

While the medical model of disability is more closely associated with habilitation and rehabilitation, it is the social model of disability that can promote the accessibility of social infrastructures, challenge prejudices and create an equal society for everyone.

An inherent aspect of the social model of disability is that it is primarily society that disables people⁶. It is the societal barriers, alienation and exclusion, and social attitudes that create the sense of ‘other’ and that limit those with a hearing and/or sight loss to fully realise the human rights that should be afforded to every individual.

It is not any individual’s medical condition that disables them and limits their access to culture, society, and their basic human rights, it is societal barriers.

⁶ Walmsley J, 2001

These barriers may be physical, such as a deaf person being unable to communicate without the use of a BSL interpreter or electronic notetaker, but they can also be caused by people's attitudes to those who are different. In this regard, prejudice can play a key role in disabling.

If society is to enable true integration of people with a hearing and/or sight loss (and, indeed, disabled people more generally), then inclusive communication is vital. It is the removal of social barriers which can allow for a truly inclusive and integrated society.

Assistive technologies and language/communication support professionals allow disabled users to bridge the gap between what they want to do, and what existing social infrastructures and frameworks allow them to do. However, the removal of prejudice relies on the tools that we use avoiding creating a sense of 'other'.

Social Geographer Mike Crang describes 'othering' as a process "through which identities are set up in an unequal relationship"⁷. This process stems from the creation of an in-group or the self, and the out-group: the other. These groups are placed in unequal opposition by attributing inferiority to the out-group⁸. While Crang discusses othering in the context of ethnic minorities, when people within the four pillars of deafness are defined with reference to their specific and varying access to communications needs, they too are othered and treated as inferior to their hearing counterparts. Inclusive communication should be designed to be inclusive to all, rather than alternative systems being created as an afterthought to avoid creating a sense of 'other'.

We must alter how society is organised and move towards an integrated society that enables those who challenge present structures and systems of 'normal'.

Failure to do so will mean that people within the four pillars of deafness are excluded from society. Further, it is not just enough to ensure language barriers are overcome: while societal barriers remain in place, sensory deprivation itself can be seen as a form of torture, and so changes must be made by society to integrate multi-sensory structures and processes into all aspects of living.

⁷ Crang, M. 1998. p61

⁸ Brons, L. 2015

What Works - Caring about Communication

When we apply the social model of disability to everyday life, the actions required to affect change become clearer and much more attainable.

This is perhaps most evident in solutions for those with physical disabilities. For example, if a person with a physical disability wishes to enter a building with a step the social model of disability states that there is something wrong with the building, not the person. Adding a ramp or stair lift may be a solution which eliminates any restriction to access⁹.

To apply this to issues of deafness, if a person who is very hard of hearing wishes to watch a video but this video does not have any captions, it is the video that needs adjusted. The addition of subtitling makes this more accessible, and additional BSL interpretation can make it fully accessible to all within the four pillars of deafness.

If a deaf person wishes to enter a building which uses an intercom entry system they are being disabled by the environment around them, by the lack of provision for those who cannot use such an entry system.

We have seen a societal shift in the planning and construction industries and new builds now must meet specific standards to ensure accessibility for those with physical disabilities. But we must now apply the same approach and methodology to designing services and communication systems. When we approach a project by asking “how can we make this accessible to everyone?” we can tackle the societal barriers that disable those with sensory impairments.

While there are many standards for ensuring accessibility for people with physical disabilities, the same cannot be said for those with sensory loss. Yet, removing societal barriers need not be a complex or complicated issue: it just requires thinking beyond

⁹ Scope 2018

the norm, thinking about inclusion and integration. We can all help remove these barriers within our everyday lives, but within a care environment a failure to remove these barriers has an impact far beyond disabling or isolating an individual. Within a care environment a failure to support inclusive communication can have a direct impact on physical and mental wellbeing.

We need to uphold and further develop standards for inclusive communication and accessible information, and promote an understanding of the fact that human rights legislation in Scotland requires these standards to be met. It is the requirement of any care setting to develop, accept and promote the effective strategies required to allow for meaningful communication between staff, visitors and service users.

Consider the following example:

A 75-year-old woman is admitted to a care home on a permanent basis. She has hearing aids in both ears. Staff increasingly judge her to be withdrawn as she rarely speaks. Meals are chosen for her and her care plan registers her lack of opinions on key aspects of her care. Her 14-year-old granddaughter is mystified about this change and quickly realises that the batteries in her hearing aids have stopped being replaced weekly. Her relatives complain and commence weekly checks on her ability to hear. Consequently, the woman returns to being a communicative and participative person. She is happier, healthier and engaged. Importantly, she regains her independence and ability to make her own choices. Staff introduce a policy of weekly checks on all hearing aids.

This example highlights the need for deaf awareness training to allow for a full understanding of the needs of those with sensory impairments.

Deaf Awareness Training

Deaf awareness training should be considered for all public-facing staff. This should include background information about deaf BSL users, deafened people, deafblind people and hard of hearing people.

Deaf awareness training encourages caregivers to think about service users who may be deaf and how they can make sure people across the spectrum of deafness have equal access and support.

This should involve training on some of the barriers deaf people face daily, with simulation of conditions being an incredibly effective method of altering perceptions and developing an understanding of the social barriers that deaf people face.

The training should include information about legislation such as the Equality Act 2010 and the Human Rights Act and how they translate to the workplace.

When people are made aware of the social barriers that deaf people face they become much more capable and willing to make the small changes required to remove those barriers. Many of the changes required are extremely simple.

Deaf awareness training can also challenge preconceptions and prejudices surrounding people with deafness. A lack of understanding of the issues and barriers that deaf people face can result in a fear of offering support.

What if I try to help this person but accidentally do something offensive? What if I accidentally talk about a new song I heard that I really liked and offend a deaf person as they can't hear it? How do I approach a deaf person who isn't looking at me and can't hear me approach, if I touch them to get their attention is that invading their personal space?

These fears exist within everyday life, and within all disabilities. A lack of understanding of how to communicate causes many people to avoid the situation altogether in fear of doing the wrong thing. A greater awareness of deaf issues and how to support those across the spectrum of deafness can help eradicate this fear.

Deaf awareness training can also help us understand how to alter society, how to make the small changes necessary to - as the social

model of disability infers - remove the disability. This could be as simple as setting standards on when hearing aid batteries are checked within a care environment, ensuring subtitles are switched on and available on the TV, providing films with subtitles, using a microphone with the hearing loop and perhaps introducing other assistive technologies.

Simple Solutions

There is a tendency to shout or raise one's voice when speaking to someone with hearing loss. While a louder voice may be easier to hear, it may not be easier to understand. As the relationship that communicators form goes beyond only verbal communication (e.g. body language plays an important role) it is easy for someone who is raising their voice in an attempt to be heard to come across as aggressive or agitated.

Consider the following:

Imagine you have a resident in a care home who is hard of hearing but also has other complex needs, perhaps living with dementia. If a caregiver appears to be shouting at that person the person will quickly become distressed and confused. We must approach inclusive communication by understanding the relationship between the communicators and the ultimate aim of creating understanding.

Good Practices for Inclusive Communication:

Face to face communication

- Speak in front of people. It is far easier to pick up that someone is talking at you and being able to see a person's lips move can aid understanding for those with hearing loss or those who can read lips
- Do not rush. Clear and concise communication requires space for understanding, think about the speed at which you are speaking

- Use clear language. Speaking clearly rather than loudly can help aid inclusive communication
- Use picture aids and/or paper and pen, if it helps.

Consider the environment

- Ensure the lighting is good and the speaker's face is not in shadow. Well-lit areas make it easier for someone who is hard of hearing to see that you are speaking to them
- Try to find a smaller, quiet space to eliminate background noises getting in the way
- Use blinds or suchlike to prevent unhelpful shadows
- Reduce distracting “visual noise”
- Add soft furnishings in spaces you use, hard surfaces can reflect sounds creating echoes and distortion.

Assistive technology

- Ensure that hearing aid batteries are checked regularly
- Can you install any other equipment? Hearing loops are commonplace in many public spaces, many staff in schools and universities use microphones, could these be used in a care environment too?
- Newer technology includes Roger pens or other forms of microphone/receiver enhancement
- Include subtitles and even BSL if necessary when creating materials and ensure that they are available in multiple formats.

Advanced Communication Support

Various methods of communication support are available for those who require more advanced support. British Sign Language (BSL)/English Interpreters, Electronic Notetakers, Lipspeakers and Communication Support Workers are collectively referred to as Language Support Professionals (LSPs).

BSL/English Interpreter

BSL/English interpreters are highly trained, specialist professionals who can be booked to attend meetings with deaf people. They will translate what is spoken in English into BSL and what is signed in BSL into English.

Electronic Notetaker

An electronic notetaker is a highly trained professional person who takes notes – usually on a laptop computer – at meetings so that deaf people can follow the proceedings. The notes can be projected onto a screen for larger audiences.

Lipspeaker

Deafened or hard of hearing people who prefer to lipread may ask for the support of a lipspeaker. These are highly trained professionals who speak without sound and who may use fingerspelling to indicate the first letter of a word to make it clearer.

Communication Support Workers (CSWs)

These professionals work in many different kinds of situations to help deaf people communicate with others. In educational settings they help the student to understand the lessons and to communicate with their teachers and other students by translating from spoken English to BSL and from BSL to spoken English, or variations such as signed supported English. CSWs may also work with deaf people with additional needs. CSWs work with the same deaf person each day which means they understand their needs and can give additional support where necessary.

Registered Qualified Language Support Professionals (LSP)

Any LSP you book should be appropriately qualified and registered with either the Scottish Association of Sign Language Interpreters (SASLI) www.sasli.co.uk or the National Register of Communication Professionals working with deaf and deafblind people www.nrccd.org.uk. SASLI holds the register for qualified Sign Language Interpreters in Scotland and NRCPD maintains the national register of all qualified LSPs. Registered LSPs must hold certain qualifications

and abide by certain professional standards. A list of relevant qualifications can be found on the NRCPD website, www.nrcpd.org.uk.

Online Interpreting

The use of online interpreting has increased recently and will most likely be more widely used in the future. When no BSL/English interpreter is available to attend a meeting – for example a doctor's or hospital appointment – the service provider may have access to online interpreting. This means they connect to an interpreter via a webcam and the interpreter communicates over the computer screen.

contactSCOTLAND-BSL

The contactSCOTLAND-BSL video relay service enables BSL users to contact all of Scotland's public bodies and third sector organisations. More information can be found at <https://contactscotland-bsl.org>.

Accessible Information

Many elements of accessible information are now being written into legislation. The new EU directive focusing on web and mobile accessibility will compel public bodies to ensure that they present information in accessible formats, however, ensuring that materials are made available to all should be considered a requirement of allowing that person to realise their human rights.

The European Union's Web and Mobile Accessibility Directive (2016) requires EU Member States to ensure *'that public sector bodies take the necessary measures to make their websites and mobile applications more accessible by making them perceivable, operable, understandable and robust'* ¹⁰. The proposed European Accessibility Act could see this extended to include private businesses, strengthening existing non-discrimination laws such as the UK's Equality Act 2010. As non-discrimination laws evolve and media content does become more accessible, the technicalities of how to create accessible information will become more mainstream and

¹⁰ European Parliament, Council of the European Union, 2016. §3

normalised.

Some basic guidelines for accessible information should always be adhered to, they include:

Websites

Information on websites should be available in British Sign Language (BSL) with captions.

Printed Material

Printed material – such as newsletters and leaflets – should be written in plain English using a clear plain font such as Arial with a minimum point size of 12. Where appropriate, images should be used, with relevant alternative text provided. Wherever possible the same information should be available on DVD in BSL with captions.

Textphones/SMART or Mobile Phones

A textphone is a telephone with a QWERTY keyboard and a small screen. Textphone to textphone calls are just phone calls using text rather than speech. These are less popular and are giving way to mobile phones and next generation text and email as well as FaceTime and Skype visual mechanisms.

Text Relay

Someone who does not have a textphone can contact a textphone user via Text Relay through an operator. Similarly a textphone user can contact a voice telephone user through the text relay operator. Again this is lessening in popularity as technology develops.

Fax and Email

A fax number and email address should always be included in contact information for deaf people who prefer to use these methods of communication. Faxes are becoming less popular as smartphones and other technology develop.

SMS

SMS means Short Message Service and is also called texting or text messaging. Messages are usually sent from one mobile phone to another. SMS can also be set up to receive newsflashes and other alerts or reminders.

TextBox

Registering with TextBox gives companies the facility to offer live written conversations with deaf people through an application on their computer or mobile phone. Please note that this is a chargeable service. Find out more from www.textbox.co.uk.

Remote/Electronic Interpreting

As technology develops, we are seeing Alexa develop speech to sign technology, remote interpreting services and huge increase in text and email. As this technology develops the costs for these items is reducing. Deaf people have had to pay for additional communication services. There are major costs for these services not always met by Access to Work or the benefits system (e.g. pension and care packages).

Promoting Independence

When inclusive communication is promoted and championed it allows for those within the four pillars of deafness to achieve independence.

The popular understanding of care is doing things for people. Within a care environment there is always a risk that we become so preoccupied with doing things for people that we forget that they can do things for themselves. We believe that the fundamental concept of care should be to promote independence.

The current trajectory of care - care contracting and an emphasis upon tasks – often, but not always, results in people who are well cared for within their community or within a care home deteriorating due to a lack of social interaction.

We need to approach care by asking what a person can do for themselves, and how a caregiver can support them to achieve independence. This is evident within the social model of disability: rather than carrying out tasks to compensate for someone's disability we need to look into how we can alter their environment to remove barriers to independence. This is as important with communication than any other form of care, and arguably more important if the impact of sensory deprivation is accepted as significant.

Specific Recommendations - Residential Care

deafscotland is concerned that, because of the lack of specialised residential care, many deaf people are cared for in local care homes where they may be the only deaf person, or within a group of people that struggle to communicate because they all have levels of hearing loss. It is therefore vital that care staff are equipped with the appropriate knowledge and training so that the needs of deaf people in their care are fully met.

deafscotland recommends a range of matters to be taken account of when developing plans for improvements around communication that have benefits for those affected by deafness. We understand the competing pressures on overstretched services and realise we are providing quite a long (not exhaustive) list of potential ideas, however we would also recommend a pragmatic approach. Look down the list at quick wins and short, medium and longer term ambitions. We would hope that improving communication would show time savings and improved impact.

Perhaps consider your plans across the four pillars and keep them simple and SMART (specific, measurable, achievable, realistic and timescaled). Are there some challenges and solutions that are most relevant for your residents? Would some actions also improve the management of challenging behaviour or dementia support?

Would there be support or partnership working that might help? Might a partnership approach lever in additional resources? Please contact us if we can help or advise admin@deafscotland.org.

1. All residential homes should be encouraged to carry out Equality Impact Assessments to ensure that the needs of deaf people are included in all areas of the home.

2. Each residential home should have an identified “communication champion”, a manager who has a thorough understanding of deaf and communication issues – with accredited deaf awareness training. They should be responsible for ensuring that services in the home are fully accessible to deaf people and be compliant with all legislation relevant to deaf people.

3. All staff who have contact with deaf residents and their visitors should have accredited deaf awareness and communication skills training and this should be delivered on a regular basis over the course of individual staff’s employment in the home.

4. Every deaf resident should receive a copy of their occupancy agreement in their preferred format. If a deaf BSL user resident receives this in British Sign Language (BSL), then the home should provide the necessary means for the resident to be able to view it whenever they wish.

5. If the residential home has deaf BSL using residents, there should be at least one member of staff present at all times with a minimum of Level 2 in BSL. All staff should be encouraged to learn BSL to Level 2. Deafened people may require other forms of communication support and that would include tactile communication for deafblind people.

6. Staff should be trained to promote good communication and encouraged to use technology in their work to communicate with residents who are deafened to ensure that these residents are not isolated.

7. Whenever a deaf resident and/or their family/guardians meet with home staff to discuss the resident’s circumstances, appropriate communication support must be provided by the home. If the home

has residents' meetings, then appropriate communication support should be provided by the home to ensure deaf residents have equality of opportunity to take part.

8. Each residential home should have connections with relevant deaf organisations in the area and encourage active links with these organisations and their deaf residents. This is especially important for deaf BSL users and deafblind people so that they have regular contact with the Deaf Community.

9. All areas of the home should have induction loops fitted as standard – including public areas and residents' rooms. Visual as well as auditory alarms should be fitted to make sure all residents and their visitors are safe. Staff should be trained in the operation and testing of these aids and appropriate records kept.

10. The home should be accessible to deaf visitors and should not rely only on telephone contact for residents and their family/visitors. Increasingly Skype and other forms of visual communication are being used. Door entry systems should have a visual aspect to them so that deaf residents and visitors can gain access to the home.

11. Residents must be able to access captions on the home's televisions and films/DVDs shown should have captions available.

12. All residents, even if they have not been diagnosed as being deaf, should have hearing tests at regular intervals. Staff should receive training on how to look after and fit hearing aids and should know where to access support for residents who use hearing aids. Each resident should have a named member of staff who will help them to put in their hearing aid(s) each day. There is a range of screening tools and hearing aid care information available on the internet.

13. Each resident should have a named member of staff with the necessary communication skills who can ensure that the resident's social and spiritual needs are catered for.

Deaf people with additional complex needs

Deaf people with additional disabilities or illnesses need specialist support to help them in their daily lives. They also need people who know how to communicate with them and who can provide a continuity of care. Many deaf BSL users with complex needs will not benefit from working with registered British Sign Language (BSL)/English interpreters; they may prefer to work with support staff from specialist deaf services who know their personal communication abilities and needs. Specialist staff can offer more appropriate and personal support than BSL/English interpreters who work in more formal situations.

There is a severe lack of accessible and appropriate care services for deaf people in the community, for example care at home and housing support services. This is especially true for deaf people with complex needs. Therefore there is a need for specific, specialised care provision to be made available so that deaf people with complex needs can have any chance of accessing an equitable service with other deaf people and their hearing peers.

deafscotland recommends:

1. Equality Impact Assessments should be carried out to ensure that the requirements of deaf people with complex needs are included in all services.
2. In order to meet the minimum Care Standards, all care staff should have access to the appropriate levels of SVQ training.
3. All care staff working with deaf people with complex needs should be trained to a minimum of BSL Level 2 – with ongoing further training when available and appropriate.
4. Organisations providing services to deaf people with complex needs must also ensure that care staff have access to additional training in order to provide appropriate care in other specialised

fields, such as autism awareness, mental health, managing challenging behaviours, first aid, monitoring and dispensing medication.

5. Staff training should also involve establishing links with agencies which work in other specialised fields, which can also benefit from the sharing of knowledge and experience.

6. There should be a recognised career structure for social workers and other care professionals working with deaf people.

7. In partnership with local authorities, health boards and specialist deaf organisations, the Scottish Government should look at the requirements of deaf people with complex needs in Scotland and make recommendations on what services should be available to make sure that these people live healthy, safe and satisfying lives.

8. When local authorities are setting rates for the personalisation agenda and self-directed support, they must take into account the cost of specialist services for deaf people with complex needs and ensure the necessary financial support is in place.

9. Public bodies involved in the procurement of services for deaf people with complex needs should involve deaf people in the planning and tendering processes. Before renewing contracts, service user feedback should be sought.

10. The specific requirements of deaf people with additional needs must be considered in financial planning by local authorities and others.

Conclusion

We live in a world where society itself is growing older by the day. Our ageing population means that more people are losing their hearing, more people are requiring society to change to allow for them to live their lives to the full, to realise their human rights.

We need to treat communication like we do health and safety. We need to remind ourselves of the importance of it. This may entail some impactful training based around simulation of situations and impairments, it may entail investing in new modes and systems for communication. Inclusive communication requires a commitment but eradicating societal barriers for deaf people can be of benefit to the wider community. A more accessible world for deaf people can and should lead to a more accessible world for all.

When we design for inclusion everyone wins.

Many of the great innovations which are now a staple part of our lives took their inspiration, in part, from breaking down barriers for those with disabilities.

Alexander Graham Bell's mother, Eliza Bell, was deaf. His father, Melville Bell was an orator and the creator of a program called Visible Speech, which used symbols and drawings to teach people with hearing loss how to speak languages they had never heard. It's rumoured that it was this that influenced Bell to study acoustics, leading to the development of the telephone.

One of the key figures in the development of the internet, Vincent Cerf, was hard of hearing. Unable to discuss his work with colleagues over the phone, he helped to develop the first IP-based information transfer systems, which went on to become the bustling web of communication that we've become so heavily reliant on today: the internet.

How many times per day do you send text messages? They now seem so commonplace, such an obvious tool, but the main reason that text messages were brought to mainstream mobile phone users in the first place was to allow deaf people to communicate.

When we design for inclusion - when we approach a problem by asking “how do I make this this work for everyone?” - we are forced to think differently, to look beyond the norm.

We are still learning, of course, and we probably always will be. We are looking for new ways to work with the old tools, and we’re challenging traditional ideas. It can be daunting, or, it could be exceptionally exciting.

Together we can remove societal barriers and create a society where deaf people have equal access, rights and citizenship.

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