HSC Health and Social Care

Regional Physical and Sensory Disability Strategy

Making Communication Accessible for All

A Guide for Health & Social Care (HSC) Staff



A Guide for Health & Social Care (HSC) Staff

All HSC staff are committed to improving people's health and social care and to make sure that people can understand the information they are given about their health and care. We also want everyone to be able to get involved in decisions that affect them. Everyone has the right to communicate. Communication is the exchange and flow of information and ideas from one person to another. It is a two way process and if there is a difficulty or breakdown there is a shared responsibility to address and resolve it.

We know that some people need information in a different format, or help to communicate or explain what they think. For example in large print, braille, easy read or by email. There are a range of different disabilities that need to be considered when making information accessible. The most commonly used form of communication within HSC is English in its spoken and written forms. A sizeable proportion of our population does not communicate this way for a variety of reasons and we need to ensure that we acknowledge and tailor our means of communication accordingly. Not being able to access information in a way that best suits their individual needs can act as a major barrier to accessing health and social care. It is important that we, as Service Providers whose core function is health and social care, recognise these barriers and do not assume that the usual ways of providing information are adequate.

This guide will assist you to make sure that people get the support with communication that they need, for example through having a British Sign Language (BSL) or Irish Sign Language (ISL) interpreter or an advocate with them. There are many different ways to communicate - speaking, writing, sign language, photographs, pictures, symbols, objects, electronic aids, as well as non-verbal communications such as facial expressions, body language, sounds and gestures.

Some people have difficulties communicating and have communication support needs.

Having communication support needs can isolate a person and make it hard for them to access services, education, get a job, make friends, stay safe, live independently and have good mental health.

The barriers faced by people with communication support needs are often created by other people and by poor communication environments. Complaints received by Health and Social Care services are frequently attributable to poor communication. It is important to remember that often a person's disability may not be obvious and that some people may have more than one disability. We all have a responsibility to make changes to our communication so that people with communication support needs are treated equally and not excluded by making changes to our own communication, creating communication friendly environments and recognising and valuing all the different ways people can communicate.

By making the small effort to become better at communicating, you will make a big difference to the lives of people with communication difficulties.

A Guide for Health & Social Care (HSC) Staff

This document presents guidelines, tips and advice and aims to:

- Help you and your service think differently about your communication
- Make you aware of current legislation
- Increase your awareness of the wide range of Communication difficulties and understand how you can change to enable more positive outcomes and experiences for people with Communication support needs
- Help you create communication friendly environments to support people, to communicate to the best of their ability.

The Guide has been produced for Health and Social care staff so that they can communicate more effectively with people who may have a disability or a communication support need. This resource has been greatly informed by the input and quality assurance from disability representative organisations – whose participation has been formally recorded in the Acknowledgements section.

This Guide looks at people with a range of disabilities and offers you advice to improve:

- Face to Face Communication
- Telephone Communication
- Written Communication
- Information on the web.

This document is colour coded so that you can easily locate specific areas of disability. This is the second edition of the Guide, which was developed as a result of the commitments within the Trusts' Disability Action Plan (DAP) and the findings of the Audit of Inequalities, as well as research and engagement with colleagues representing the Disability sector. The initial Guide was subject to annual review, as committed to in the Trust's DAP. This review will continue to be carried out annually in partnership with colleagues from the Disability Sector.

What are the benefits of reading this document?

- Increased awareness of communication support needs
- Increased confidence in adapting your own communication skills
- Increased awareness of inclusive communication
- Increased positive regard for people with communication support needs
- Increased knowledge of how to create positive communication environments
- Will enable you to create positive experiences for people with communication support needs accessing services
- Increased awareness of communication strategies and reasonable adjustments to support people with communication support needs
- Knowledge of accessible information
- Knowledge of visual approaches
- Knowledge of environmental equipment that could help people with communication support needs.

Alternative formats

This document can be made available in alternative formats upon request. Please contact your Equality Unit.

Acknowledgements

The HSC organisations have recently updated this handbook to take account of the diverse communities availing of its services and would like to express sincere thanks and appreciation to all those who contributed to the development and revision of this useful resource for staff.

HSC Organisations would also wish to thank the Belfast HSC Trust for being the custodian of this guidance and for keeping it up-to-date and relevant.

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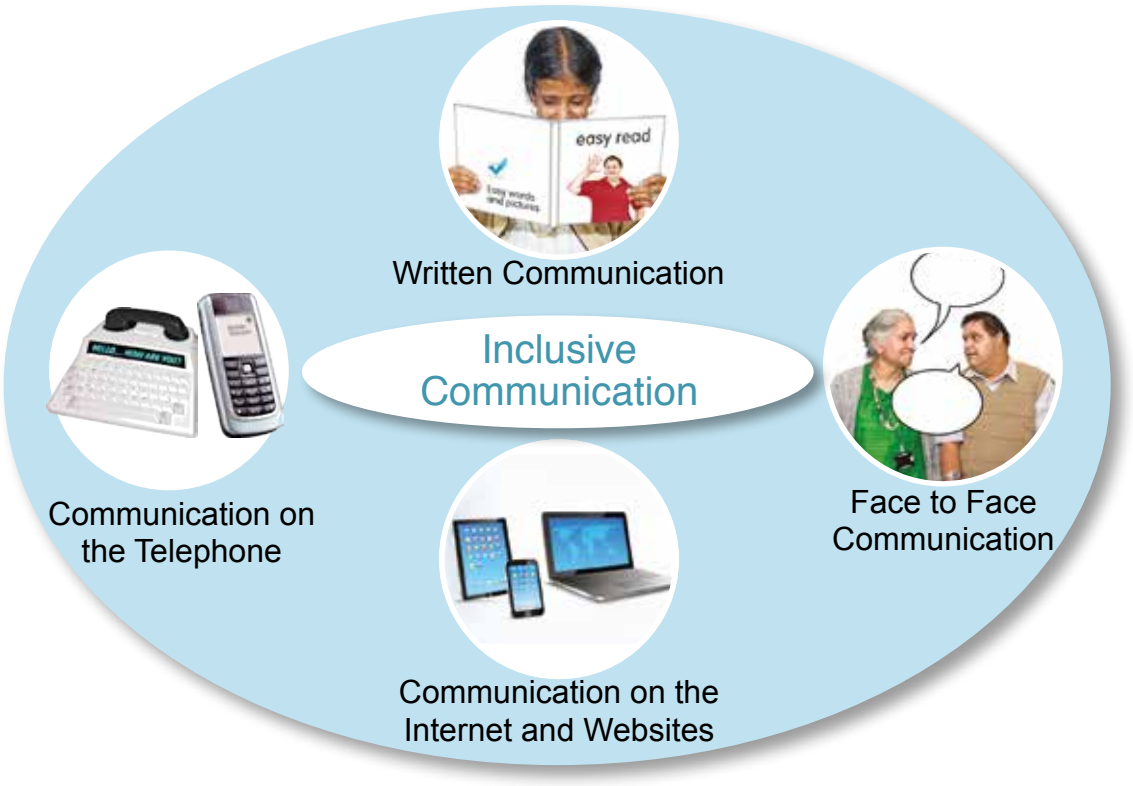
Inclusive Communication

What is Inclusive Communication?

Inclusive communication is sharing information in a way that everybody can understand, enabling people to express themselves in any way they find easiest.



What are Communication Support needs?

People have communication support needs or communication difficulties if they need support with understanding, expressing themselves or interacting with others. They may have had their communication difficulty all their lives like some people with a learning disability or some people who stammer. They may have acquired their difficulties for example following a stroke, head injury or degenerative condition. It may not always be obvious at first that somebody has a communication support need.

People with communication support needs can face exclusion and discrimination. As providers of Health and Social Care, it is important that we are proactive in effectively addressing communication support needs in partnership with service users. In the Northern Ireland 2011 census 29,871 people identified communication difficulty as their main long term condition.

Inclusive Communication

Communication disorder is the most common disability

- 1 in 5 people will suffer from communication difficulties at some point in their lives
- 1 in 3 stroke survivors have speech, language and communication needs
- More than half of children in deprived areas do not have the necessary speech and language skills needed to learn to read and write
- 90% of the 1.5 million people in the UK with a learning disability also have speech, language and communication needs
- Nearly two thirds of young offenders have speech, language and communication needs.[1]

Why does inclusive communication matter?

Everyone needs to make sense of information and use services effectively. However, communicating can sometimes be confusing. We all experience misunderstandings on occasion which can feel frustrating and distressing. People with communication support needs face daily challenges in understanding what is being said to them. People can struggle to make sense of written information. Many people find communicating their needs difficult and therefore those needs may not be met.

Laws exist, good practice exists but discrimination persists! When communication is not inclusive: -

- People's needs are not met
- Some of us are excluded from school, education, work, healthcare, police, fire, leisure and social services
- People do not use services effectively
- People can become stressed in their work and need to take time off due to stress related illness. This costs money.

In years to come there will be many older people in Northern Ireland. Many of us will develop communication support needs as we get older. Establishing good practice now will benefit many in the future.

Difficulties with speech, language and communication can severely limit a person's participation in family life, the community, education and the world of work. Everyone needs to understand information to access services effectively. Inclusive communication will enable people with communication support needs to:

[1] http://www.rcslt.org/about/young_offenders_and_criminal_justice/intro

Inclusive Communication

- Gain full access to services
- Understand what service providers are telling them
- Be understood
- Have a more positive experience of services
- Maintain the motivation to take up and stick to services that make positive change to their lives.

Inclusive communication is a requirement by law. There is legislation in place in Northern Ireland which makes it unlawful to discriminate against people with disabilities. The Disability Discrimination Act 1995 prohibits discrimination and requires health and social care providers to make reasonable adjustments to ensure that services are accessible. An example of a reasonable adjustment would be providing information in an accessible format. Inclusive communication helps Trusts meet their equality and legal commitments.

Since 2006, public authorities must also have due regard to the need

- To promote positive attitudes towards disabled people, and
- To encourage participation by disabled people in public life.

Section 75 of the Northern Ireland Act (1998) requires public authorities to have due regard to promote equality of opportunity across a number of grounds, including disability.

The Human Rights Act (1998) also makes human rights a part of local legislation and means that public authorities must respect, protect and uphold the rights of all service users.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) provides specific human rights protections for persons with disabilities, including accessibility of information and communication. The Convention states that Persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

There are 5 standards across Health and Social Care in Northern Ireland which seek to improve the patient and client experience: these are respect, attitude, behaviour, communication and privacy and dignity. The communication standard stipulates that all health and social care staff communicate in a way which is sensitive to the needs and preferences of patients and clients. It defines clear communication as ‘understanding and feeling understood’[2].

Also, NHS draft accessible information standards 2014 state that professionals MUST identify and record the information and/or communication needs of their patients and

[2]It is envisaged that these draft standards will be formally ratified by June 2015

Inclusive Communication

service users – and where appropriate their carers or parents – where such needs relate to or are caused by a disability, impairment or sensory loss.
Services that exclude people by not responding to their communication needs waste time and money. Inclusive communication can save both time and money for service providers and the people who use services, and can improve health outcomes for people with communication support needs and the wider community.

Making communication inclusive and environments communication friendly saves money, helping Trusts to meet their financial commitments by ensuring that resources are targeted where they are needed and meeting the communication needs. For example, accessible appointment letters reduce missed appointments, taking the time to explain treatments and medications can prevent costly re-admissions, and making health information accessible can help prevent health conditions.

Inclusive communication will help tackle significant inequalities in Northern Ireland. We have a responsibility to ensure our services are high quality, continually improving, efficient and responsive to local needs. We need to be welcoming and inclusive to all who live here and avail of our services.

Whose responsibility is it?

All Trust staff must take responsibility for their own actions and communication and how they affect others. Staff should be flexible in the way they communicate and deliver services.

You should find out if people have any information or communication needs. For example, you should ask people if they need information in easy read or large print or braille or by email. You should ask if people need an advocate or a Sign Language interpreter. You should record or write down people's needs in the same way. This should mean that other organisations and other staff are informed and can understand what people's needs are. It should mean that when someone goes to a service they have been to before, their needs are already known and will be adequately met. You should make sure that if someone has information or communication needs this is very clear in their notes or records.

For advice or further information, contact your Trust's Equality Unit.

Inclusive Communication

Watch and Learn is an acronym for the 10 Top Tips to help you think about and Change your Communication



Willing

Show that you want to communicate with your **whole body** and the way you speak not just the **words** you use. **Listen. Stop** what you are doing and show you are listening. **Tune in**.



Ask the expert

People are **experts** in their **own communication**. You may be able to ask them how best to communicate. They may have information to describe how best to support communication eg. a communication passport. Look at the way they are communicating and value that communication by using that communication back to them. Adjust ***your*** communication style. It is easier for you to change your communication to make sure the person really understands. This might mean using **easier words** and **shorter sentences**.



Time

Be **patient**. No one wants to communicate with someone who is impatient. If needed, allow **extra time** to communicate and give people plenty of time to respond.



Check understanding

Do not run on ahead and assume that someone understands.



Have a go

Have the confidence to have a go and keep trying. Challenge unhelpful attitudes. Communication accessibility is as important as physical or sensory accessibility.

Inclusive Communication



Look

Make eye-contact. Look at the person that you are talking about, and to. Make sure you go up to the person and get their attention before you speak.



Environment

Think about the communication environment, eg.

- Reduce noise and improve lighting, use accessible signage
- Remove physical barriers to communication
- Make it clear where people can go to get help and advice
- Use communication tools.

Be aware of the many communication tools that are available, eg. Talking Mats, Hospital Passports, www.easyhealth.org.uk



Acknowledge

You can often understand how someone is feeling from their body language, facial expressions and gestures. Let someone know that you recognise how they are feeling.



Respect

Treat everyone with respect by speaking directly to them. The person should be approached with respect and without prejudice or assumptions. Positive regard for everyone. The only assumption is to assume that everyone has the ability to participate.



Now

You are required by law to make reasonable adjustments now. Think about what adjustments you can make to ensure that every person will be able to make best use of the opportunity today, eg.

- Provide extra time, perhaps a double appointment
- Create a quiet place for the person to wait
- Allow the person to be first so they do not have to wait
- Send information so they can prepare in advance
- Provide easy read materials supported by photographs
- Have the meeting in a place and at a time of their choosing
- Allow a carer or supporter to be present
- Have visual aids to demonstrate what is going to happen.

Statistics relating to Disability

There are an estimated 300,000 people who are deaf, have a hearing loss or tinnitus in Northern Ireland.[3]

There are an estimated 46,000 people in Northern Ireland with significant sight loss[4]. Approximately 10,400 people in Northern Ireland have a dual sensory impairment, known as Deafblindness.[5]

In 2011 it was estimated that there were 36,197 people with a learning disability in Northern Ireland.[6] In total for 2012/13 the HSC Trusts had contact with 9,192 people with learning disabilities[7].

Around 0.6% of the population, or 10,000 people in Northern Ireland could benefit from using Alternative and Augmentative Communication (AAC).[8]

Figures on stammering in adulthood show that 1% of the adult population stammers - that's around 459,000 adults in Britain. About 4 men stammer for every woman who stammers.[9]

Every year, around 4,000 people in Northern Ireland have a stroke and there are approximately 10,000 people with Aphasia in Northern Ireland.[10]

It is estimated that approximately 2,000 people a year in Northern Ireland sustain a brain injury.[11]

There are approximately 20,000 people in Northern Ireland[12] with Autism Spectrum Disorder (ASD) – around 1 in 86 (1 in 50 in some areas).

It is estimated that at present in Northern Ireland there are 19,000 people living with dementia.[13]

There are 10 million people in the UK living with a neurological condition which has a significant impact on their lives and they will require help for most of their daily activities.

This will include most people with motor neurone disease (MND), many of those with primary and secondary progressive multiple sclerosis (MS) and other progressive neurodegenerative conditions, those with severe brain injuries, people who have had a serious stroke (including brain haemorrhage) or those who have advanced dementia.[14]

[3] Action on Hearing Loss
[4] RNIB
[5] Sense
[6] Mencap NI
[7] http://www.niassembly.gov.uk/globalassets/documents/raise/publications/2014/employment_learning/5014.pdf
[8] http://www.communicationmatters.org.uk
[9] British Stammering Association
[10] Stroke Association
[11] http://www.hscboard.hscni.net/RABIIG
[12] Autism NI
[13] Improving Dementia Services in Northern Ireland: A Regional Strategy, November 2011, DHSSPSNI
[14] 'NeuroNumbers' publication, the Neurological Alliance - http://www.neural.org.uk/store/assets/files/20/original/NeuroNumbers.pdf

Communicating with people who are deaf or have a hearing loss

There are many differences in the causes and levels of deafness and hearing loss so different people communicate in different ways. For example:

- Use of hearing aid or cochlear implant
- Lip-reading
- British Sign Language
- Irish Sign Language
- Speech to Text or electronic note-taking.

Don't be afraid to ask the service user their preferred method of communication.

Face to Face Communication

- Find a suitable place to talk, with good lighting, away from noise and distractions. Make sure you have the person's attention before you start speaking and check that the person you are talking to can understand you. Be patient and take time to communicate properly
- Look directly at the person and to keep your hands away from your face. Look at the person who is deaf and don't turn your face away
- Find out if the deaf person requires a Sign Language Interpreter. There are 2 types of Sign Language used in Northern Ireland – British Sign Language and Irish Sign Language. Find out which language is required before booking an interpreter. If an interpreter is involved in the conversation, remember to focus on the deaf person and not the interpreter
- Don't assume that if someone wears a hearing aid they can hear you easily
- Find out if you have access to a hearing loop system to assist people with hearing aids and make sure you know how to use a loop system
- When talking to a deaf person find out if they can lip read (in writing if you need to). Keep a pen and paper handy in case you need to write anything down. Remember to write clearly and legibly
- Speak clearly but not too slowly. Do not exaggerate your lip movements; use normal lip patterns, facial expressions and gestures. Do not shout as this is very uncomfortable for a hearing aid user and appears aggressive. Remember to use natural facial expressions and gestures
- If you are talking to a deaf person who is with a hearing person, don't just focus on the hearing person
- If someone does not understand what you have said do not keep repeating it - try saying it in a different way
- Use a Speech to Text facility if available.

Communicating with people who are deaf or have a hearing loss

Telephone Communication

- Use a Textphone if you and the person you are trying to contact both have one
- Use SMS / mobile phone texting where possible and appropriate
- Many clinics invite service users to telephone in order to make an appointment. Please consider having an alternative to telephone for this purpose, such as a texting facility, to ensure that all service users have equal access to services.

Written Communication

- Remember that if a person uses Sign Language, this will be their first language, not written English
- Keep written sentences short, use plain English and don't waffle. Avoid jargon and unfamiliar abbreviations.

Information on the Web

If you are producing online information that contains audio, include an alternative to this such as a Sign Language interpreter and subtitles.

Useful Resources

Contact your HSC Sensory Support Team for advice and here are examples of organisations who can help:

Action on Hearing Loss
Northern Ireland Deaf Youth Association
Signature
British Deaf Association
National Deaf Children's Society
Hearing Dogs for Deaf People
Hands That Talk

Communicating with people who are blind or partially sighted

Inaccessible information is one of the major barriers for blind or partially sighted people.

This can result in loss of privacy as a friend or relative (even a child) may have to read a letter/correspondence which might contain sensitive information. If people are unable to read their appointment letters they are likely to miss appointments. This could have a detrimental effect on the health of the patient. In addition it means that appointments are lost and waiting lists increase.

The physical accessibility of premises is also a major consideration for people with sight loss.

Face to Face Communication:

- Address people who are blind or partially sighted directly. Don't speak to the person accompanying them instead. Identify yourself and others in the room
- Remember that for each individual concerned their preferred communication format will be very important. Ask individuals what their specific requirements are. A simple question like 'What is your preferred reading format?' can save time and money, and is a legal right for the individual concerned
- Describe any new area to the person with sight loss.This is particularly important when a person with serious sight loss encounters a new environment such as entering a room for the first time (eg. do not leave a blind person at the top of a flight of stairs without telling them about the stairs etc.). It is important to describe the immediate environment particularly if it is likely to be hazardous
- The person may need to know where the exits, toilets and seating are in relation to their current position
- Explain where you place items eg. 'There is a cup of coffee in front of you, just to the right.'
- Use regular vocabulary. Don't get hung up on using words like 'See you later' or, 'Did you see Coronation Street last night?'
- Tell the person when you are leaving the room. Remember, people with serious sight loss don't have the visual cue of seeing someone leaving. It's also very important as they may be standing around waiting after you have left. You will also need to let the person know when you have re-entered the room.

Telephone Communication:

- Consider the use of text messaging. Many people with visual difficulties can nowadays access text and email messages via their smart phones.

Communicating with people who are blind or partially sighted

Written Communication:

- Consider the accessibility of printed documents before printing. Clear print should be at least size 14. Font should be clear, such as Arial
- Think about the type and quality of paper you print onto as some types of coloured and handmade paper can impair the contrast between the background paper and the text or image being printed. The contrast between text and background should be as high as possible to improve legibility. Consider the finish on your paper as this is important. A quality matt finish works best for most people as there is no glare
- Do not laminate paper
- Remember that large print is not a precise term, and some people will want a larger font than others. Conventionally, it is defined as 18 point or above
- Do not write full words in capital letters
- Braille remains a key means of literacy for a number of people, especially but not exclusively, for those who have sight loss relatively early in life.

Information on the Internet and websites:

- Consider 'Daisy' (Digital Accessible Information System) or MP3 format for material of any great complexity. It facilitates fast and effective reading, easy navigation, indexing and book marking
- Email communication is becoming more widely used by people with sight difficulties. Information via an email attachment, which can be accessed using screen reading software, provides full and equal access.

Useful Resources

Contact your HSC Sensory Support team. Below are some suggestions of organisations who can help:

RNIB See it Right Guidelines

Royal National Institute for Blind

Guide Dogs for the Blind

Communicating with people who are Deafblind

Deafblindness is a combination of sight and hearing loss that can severely affect a person's ability to communicate with others, access important/essential services and get about on a daily basis (mobility), which can often lead to loneliness and social isolation.

People of all ages can have a sight and hearing impairment. It may have been from birth, or more likely due to sensory deterioration later in life, known as 'age acquired' deafblindness. Approximately 70% of deafblind people are elderly with an acquired impairment. Most deafblind people have some vision and some hearing, to varying degrees.

With a little patience and understanding you can greatly improve the experience of a deafblind service user that you come into contact with. It is always best to speak to the person to find out the best way to provide support and information for them, as each individual will have different needs.

Face to Face Communication

- Make sure you have the person's attention before trying to communicate with them
- Gently touching the top of the deafblind person's arm is a common way of attracting their attention without startling them
- Identify yourself clearly
- Check that you are in the best position to communicate, (with the light on your face, not in shadow)
- Avoid noisy places and background noise
- Adapt the conditions to suit the individual
- Use 'Clear Speech' – This means speaking clearly, a little slower, and a little louder than usual, but don't shout
- Make sure your lip patterns are clear without over-exaggerating
- Check if the other person can hear and understand you
- Keep your face visible – don't smoke, eat, or cover your mouth while you are speaking
- Use gestures and facial expressions to support what you are saying
- If necessary, repeat phrases or re-phrase the sentence to assist the person to understand what you are saying
- Be aware that communicating can be hard work for both you and the service user, so regular communication breaks.

Communicating with people who are Deafblind

Telephone Communication

- Some deafblind people have a certain amount of hearing and can therefore communicate via a standard telephone
- Use a Textphone (if you and the person you are trying to contact both have one). Some deafblind people may have access to the telephone through their computer and with the use of a Braille display or large character software
- Consider using Text Relay (known as Typetalk prior to March 2009) to communicate with a deafblind person, if the person you are trying to contact has a text telephone.

Written Communication

- Try writing things down. You might need to experiment with different sizes of letters and different coloured paper and pens. If using a computer, Verdana Font size 18 is good
- Most deafblind people cannot read Braille. Braille is a medium which allows a non-sighted person to read text by touch, and is also a method for writing tactile text. The Braille code is physically presented as raised dots, usually arranged in cells.

Sign Language

Deafblind people, with little or no sight and hearing can often use finger spelling, called **'Deafblind Manual'**, where each letter of the alphabet is represented by a symbol, which is formed on the left hand of the deafblind person, with your fore finger. Each word is therefore spelt out onto the deafblind person's left hand, letter by letter.

Alternatively, you can use **'Block spelling'** where you simply draw (using your fore finger) each letter of each word, in capital letters, onto the palm of their left hand. Remember to use the whole palm for each letter and keep the shape of each letter as clear as possible.

Some deafblind people have significant hearing loss but have residual useful sight. These people will often rely on British Sign Language (BSL) and may need a communications guide to use BSL to let them know what you are trying to say to them.

Useful Resources

You can speak to HSC Sensory Support Teams. Here are some organisations who can help.

Sense

Deafblind UK

Signature

Communicating with people who have a learning disability



"Learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life." Mencap

Communicating with people who have a learning disability

	Up to 90% of people with learning disability have communication support needs, with half having significant difficulties. Everyone can communicate but some people do not use words. There is a wide range of communication difficulties but the barriers to successful communication are often due to the environment and other people.
	Some people may have difficulties maintaining attention and concentration in order to communicate successfully.
	Others may have sensory difficulties like hearing and vision.
	Some people may not understand speech, writing or pictures. They may give the impression that they understand. Many people overestimate how much people with learning disabilities understand.
	They may have speech problems, their speech may not be clear, they may not have a sufficient range of vocabulary or be able to construct clear sentences. They may not have any speech and rely on other ways to get their message across.

Communicating with people who have a learning disability

	Some people have a problem understanding the rules to social interaction.
	Many people with profound and multiple learning disabilities (PMLD) have extremely limited communication which may be restricted to behaviours such as eye gaze and changes to facial expression.
	People with a learning disability and especially those with profound and multiple learning disabilities (PMLD) are among the most excluded and disadvantaged people in today's society. All too often their attempts to communicate are ignored. It is important that everyone is valued equally and included.
Face to face	
	Value all communication. If verbal communication is difficult find out about a person's unique way of getting their message across. This may be their non-verbal communications, their use of objects, pictures, photographs or signs. They may have a communication passport. Don't be afraid to ask and talk to people who know the person well. Always talk to the person directly to show they are valued and included. Get the person's attention; say their name, before you say anything. Keep your sentences short and simple use everyday words. Remember some people will only understand 1, 2 or 3 key words. Use gestures, facial expression and body language to supplement words. Take the time to start listening and become familiar. Have a positive caring attitude and be interested in communicating.
Telephone	
	Some people prefer to get information face to face and find the telephone difficult. Speak slowly and clearly. Explain who you are and what you are calling about. Check the person has understood; ask them to repeat back or answer questions.
Written Information	
	Use pictures, easy words and short sentences to make written information easier to understand. Some people will need a person to go through easy read written information, face to face.

Communicating with people who have a learning disability

Information on the Internet and Websites



Websites need to be designed to meet the highest accessibility standards and be easy for people who have difficulty reading and with mouse control. To check if a website is accessible look for the following:

Easy read - All content is created with plain English and pictures. Information is broken down into small manageable chunks. **(See Appendix for Easy Read Guide)**

Text resizing - Many people have difficulty reading small print. Check there is an easy way to change the size of the text.

Colour - Some people have difficulty reading text of certain colour combinations. Check that there is an easy way to change the colour scheme.

Video - Video is by far the best way to make information accessible to people with little or no reading skills.

www.easy-read-online.co.uk

Useful Resources

Mencap is the leading charity of learning disability. They have many useful guides and resources to support good communication with people with learning disability. Here are just a few excellent resources.

A guide to communicating with people with profound and multiple learning disabilities.
https://www.mencap.org.uk/sites/default/files/documents/2012.340%20Raising%20our%20sights_Guide%20to%20communication_FINAL.pdf

A guide to communicating with people with learning disability.
http://www.mencap.org.uk/about-learning-disability/information-professionals/communication/communicating-people-learning-disability

A guide to communicating with people with learning disability easy read.
http://www.mencap.org.uk/node/6186#node-6186

This communication guide is aimed at a national level and focuses on what 'good' looks like and what needs to be in place to meet the communication needs of people with PMLD.
http://www.mencap.org.uk/sites/default/files/documents/2009-02/2008.292%20Mencap Guide Communicating with PMLD.pdf

How to make written information easy.
http://www.mencap.org.uk/sites/default/files/documents/2008-04/make%20it%20clear%20apr09.pdf

Communicating with people who have a learning disability

The Royal College of Speech and Language Therapy (RCSLT) have produced five good communication standards. These five standards are reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings. Everyone needs to know what good communication support 'looks like' and what reasonable adjustments they can expect. The five good communication standards:

- **Standard 1:** There is a detailed description of how best to communicate with individuals
- **Standard 2:** Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services
- **Standard 3:** Staff value and use competently the best approaches to communication with each individual they support
- **Standard 4:** Services create opportunities, relationships and environments that make individuals want to communicate
- **Standard 5:** Individuals are supported to understand and express their needs in relation to their health and wellbeing.

Communicating with people who have a communication difficulty

Guidelines for Communicating with People who have Communication Support Needs

There are many sections in this document giving advice on specific conditions that can result in communication support needs. However there are many other communication support needs which have not been covered in this document.

Many children can have a delay or disorder in their speech or language skills and some of these difficulties will continue all their life. Some people can have difficulties with their voice or social use of language. At times of critical care, people often have communication support needs. Some people can have communication support needs associated with other conditions for example, cerebral palsy, cleft lip/palate, mental health difficulties, bilingualism, and dyspraxia.

Support All Forms of Communication

- Encourage and validate the use of any communication techniques
- Use pictures or other aids to help with word finding difficulties
- Encourage pointing and other gestures
- Encourage facial expressions
- Encourage writing and drawing.

Remain Calm and Positive

- Smile and remain interested even when conversation strays
- Maintain a calm voice, remain as relaxed as possible
- Focus on what the person can do, not what they can't do
- Look for opportunities to support interaction.

Keep it Simple

- Speak in short, concise sentences
- Rephrase to keep topic focused when person is confused
- Respond immediately to communication attempts
- Provide clear choices between no more than two possibilities.

Communicating with people who have a communication difficulty

Reduce Frustration

- Request more information on a topic if unclear
- Avoid quizzing just to get the “right” answer
- Do not directly contradict the person even if they are wrong
- Draw focus away from frustrating or embarrassing problems.

Be Polite

- Make sure the person is willing to have a conversation
- Maintain eye contact (if culturally appropriate)
- Reassure and support the person if stuck or frustrated
- Thank the person for having a conversation.

Be Aware and Informed

- Monitor changing needs for communication support
- Practice using all communication strategies yourself
- Role play with friends, family and therapists to understand how to handle communication breakdowns.

Communicating with a person who uses AAC (Alternative and Augmentative Communication)

"Augmentative and Alternative Communication (AAC) is the term used to describe methods of communication which can be used to supplement the more usual methods of speech and writing when these are impaired. AAC may include unaided systems such as signing and gesture, as well as aided techniques ranging from picture charts to the most sophisticated computer technology currently available. AAC can be a way to help someone understand, as well as a means of expression."

Taken from Communication Matters: Focus on First Steps, Developing Communication Skills for Individuals with Multiple Disabilities (2012).

Being a Communication Partner

Communication is a two way process. The person "speaking" and the person "listening", also known as the "communication partner", are both equally as important. The communication partner plays a vital role in interpreting the individual as they communicate. This may include interpreting meaning from vocalisations, movements and gestures.

To succeed at understanding the individual, it is essential to be patient, offer plenty of time and remain positive in relation to the person's communication style.

Top Tips for Communicating with a person who uses AAC

Everyone has their own style of communication. AAC users are just the same and will have their own way they prefer to communicate.

- Ask the person is there anything you need to know in order to support them to communicate
- If the person is unable to tell you this, find out from those who are close to the person how they usually communicate. This allows you to concentrate on your conversation. There may be written advice available outlining this from the person's family or Speech and Language Therapist
- Let the person know if this is your first time communicating with a person who uses AAC. They will then be able to help you as much as possible
- Set aside more time for communicating with a person who uses AAC – even for short interactions
- Create a quiet environment with reduced background noise. This allows you to concentrate on the conversation
- Face the person you are speaking with. This allows you to pick up on clues such as facial expressions, gestures and body language. Make sure you look at the person you are communicating with and not their assistant. Maintain good eye contact with them as you would with someone who is able to speak aloud
- Find out the individual's Yes/No - When people are unable to say 'yes' or 'no', it is important to find out if they can indicate these responses and if so, how they usually do this. You could ask the person, "Show me how you say YES" or "Show me how you

Communicating with a person who uses AAC (Alternative and Augmentative Communication)

say NO". A range of methods may be used including looking up for 'yes' and down for 'no' or blinking their eyes once for 'yes' and twice for 'no'. The person may have devised their own way of communicating 'yes' and 'no' and it can be very helpful to know what this is during conversation

- Wait for a reply when you ask a question. It can take longer for the AAC user to respond, so make sure you give them enough time to do so
- Try to keep what you have to say short and simple, so there is opportunity for the person who uses AAC to speak
- Avoid finishing off people's sentences for them. This can often lead to misunderstandings. The person may miss clues from your facial expression when they are looking down at their AAC system
- Try to focus on one conversation topic at a time. Be clear when you wish to change the topic. The person may miss clues from your facial expression when they are looking down at their AAC system
- Invite questions from the AAC user. It is often difficult for them to interject and ask questions during the conversation
- Check that you have correctly understood the person by rephrasing what they have said to you back to them
- Check for any misunderstandings. Monitor the person's facial expression and if there is any sign of confusion, ask if they could repeat themselves or clarify what they meant.

If you get really stuck, check the following:

- Who are we talking about?
- The situation we are talking about?
- When did the situation take place – in the past, present or is it still to take place?

Sometimes you or the AAC user may need a break from the conversation. It can take more concentration than usual and can be very tiring for both the speaker and communication partner. Don't be afraid to ask the person if you can take a break. Make sure you come back to finish off the conversation. If you feel the AAC user is getting tired, ask them if they would like to take a break.

Ending the conversation - usually we use non-verbal clues to end conversations, such as reducing eye contact. However the AAC user may miss these clues as they look down at their AAC system. You may need to mention when you need to go and to give them time to say anything else they wish to.

Communicating with people who use AAC does get easier with practice!
You will become more skilled the more that you converse with AAC users. Remember that people who use AAC do want to talk to you and using these tips you should feel more confident having a conversation with an AAC user.

Adapted from Communication Matters: Focus on Speaking with Someone who uses AAC (2012).

Communicating with people who stammer

As stammering presents itself in different ways, people who stammer won't all sound the same. Some people struggle to speak and use repetitions, prolongations, "filling-in" words like "well", "um", "you know" or there may just be silence initially because the person is having a silent block. There may be sounds you can't understand. It is important to remember that a stammer may result in silence for a while. A person may well also insert or change words to try and help them speak eg. "Well, my address is..." rather than coming straight out with the address, which they are having difficulty saying.

Face to face Communication

- Listen
- Maintain normal eye contact
- A person who stammers will often need extra time - trying to hurry the person often makes the stammer more severe. Allowing extra time needs to happen informally in individual situations
- Do not finish the person's words or sentences
- In general it is best to just wait and let the person say what they want, rather than making a comment.

Telephone Communication

- People who stammer often find telephone calls more difficult than speaking face-to-face
- People who stammer can be disadvantaged by telephone answering machines which cut off after perhaps a couple of seconds of pause in speech. This may terminate the message in the middle of the person trying to say something. The same applies if the machine has a maximum message length set which is too short
- Voice recognition systems should include an option to press a key to speak to a real person either in the initial menu or the first time a person is not understood
- Don't just hang up; be willing to listen
- Don't say someone else must call.

Useful Website Addresses

British Stammering Association

- A group has been established in Northern Ireland; Northern Ireland Support for Stammering and Dysfluency, which aims to support people who stammer and improve awareness of stammering and its effects to the wider public. If you would like more information on this Group the contact email is: taylor.moore@hotmail.co.uk
- There is a best practice guide for human resource, personnel and line managers: "Recruiting and developing employees who stammer"; http://www.stammering.org/employer_booklet.html

Communicating with someone after a Stroke or Aquired Brain Injury

1. Aphasia

Aphasia is a communication disability that can occur following a stroke or head injury. It can affect a person's ability to speak, read, write and to use numbers. People have described it as like always having "a word on the tip of your tongue." It will affect each individual differently and is caused by damage to the language centre of the brain. It often hides a person's thoughts, opinions, personality, intelligence and level of competence – however people with aphasia are intelligent, able to hear, able to make decisions, and able to communicate. Aphasia is sometimes known as dysphasia.

Face to Face Communication:

The Watch and Learn top 10 tips on pages 8 and 9 are useful strategies for communicating with a person with aphasia.

Also:

- Gain the person's attention before speaking
- Use short, simple sentences
- Emphasise key words
- Write down key words
- Slow down your rate of speech
- Keep to one topic at a time
- Use gesture or body language to back up or reinforce what you are saying
- Check understanding by repeating or recapping. Ask **" yes ✓" "no x"** questions to confirm. **Yes** ✓ and **No x** can be written down if necessary and the person with aphasia encouraged to point to target.

Written Communication

- Use pictures that are relevant
- Do not rely on clipart pictures as they are not always helpful
- Use black writing on a white background
- Embolden key words
- Do not have too much information on the page
- Use font size 14-18
- Use a clear font – Arial or Verdana
- Check the readability of your material. Flesch Kincaid measures readability and recommends the reading level of 5 maximum (a lot of healthcare information is at a level of 9 or 10). The Flesch Reading Ease Score is available on Word

Communicating with someone after a Stroke or Aquired Brain Injury

- Use the Plain English Campaign free guide - A-Z of alternative words
- Use a clear layout
- Do not use inferences, idioms etc.

Useful Resources

'Ten top tips for talking with people with Aphasia'
http://www.ukconnect.org/upload/0540_FINAL-connect_topTips_web.pdf

'I have Aphasia'
http://www.speakability.org.uk/Aphasia+Information/speakability i have aphasia how you can help me

'Accessible Information – making information accessible for people with aphasia'
http://www.stroke.org.uk/resource-sheet/accessible-information-guidelines

The Stroke Association Northern Ireland
Connect - The Communication Disability Network
The Royal College of Speech and Language Therapists

2. Acquired Brain Injury

As well as these problems with language, it's important to be mindful of the fact that individuals may also have co-existing difficulties as a result of their acquired brain injury. These can impact significantly on their ability to communicate effectively and efficiently. Appropriate arrangements, adaptations and allowances must be made.

- Speech

  DYSARTHRIA (unclear or slurred speech)
  (Refer to advice section previously entitled 'communication with people who have a communication support needs' - page 21)

- Cognition

  Memory
  Attention and concentration
  Planning, organising and problem solving
  Speed of processing information

Communicating with someone after a Stroke or Aquired Brain Injury

- Emotional and behavioural responses

  Agitation, anger or irritability
  Lack of insight and awareness
  Impulsivity and disinhibition
  Inappropriate laughing/crying
  Apathy and poor motivation
  Anxiety
  Inflexibility

- Social Interaction

  Interpreting social situations
  Reading facial expression, body language, tone of voice
  Taking turns appropriately
  Using appropriate vocabulary
  Understanding humour and sarcasm.

Adapted from 'Head Injury – A Practical Guide.' Trevor Powell. Winslow Press (1994).

Brain Injury is often described as a 'Hidden Disability.' Many people who have survived brain injury report that one of the biggest barriers to being understood is the fact that many of the effects of brain injury are not visible.

Useful Resources

http://braininjurymatters.org.uk/
http://www.cedar-foundation.org/
http://www.headway.org.uk/

Communicating with people who have an Autism Spectrum Disorder (ASD)

Autism is a spectrum condition, which means that, while all people with (ASD) autism spectrum disorder share three main areas of difficulty, their condition will affect them in different ways. The 3 main areas are social interaction, social communication and social imagination.

Communication challenges of ASD vary. Many people with ASD prefer communicating through the written word rather than face-to-face or over the telephone. This is because communicating in writing does not require the person with ASD to read non-verbal cues such as facial expressions or hand movements. Many people with autism have difficulty processing everyday sensory information and as they struggle to deal with all this information they are likely to become stressed or anxious, and possibly feel physical pain. This can result in challenging behaviour.

Face to Face Communication

- Give people plenty of notice to prepare themselves for an appointment
- Do not change an appointment (without good reason)
- If you do have to change an appointment, give as much advance warning as possible
- Use clear and accessible language - do not use complicated words, abbreviations, or jargon
- Be mindful that people with ASD can be sensitive to some sounds, smells etc.
- Avoid jargon or abbreviations
- Avoid non-literal language such as metaphors; because of their literal understanding, people with ASD are unlikely to comprehend such phrases
- Don’t rely on something being inferred through language - be explicit.

Written Communication

- Give people adequate time to read information and to discuss the content with others before responding
- Let people know who they should contact with queries or for more information and what to do if that person is unavailable
- Use images or pictures to support spoken or written language.
- Use visual prompts – words followed by a simple visual illustration, as used in easy-read documents
- Use short sentences and allow time for the person to process
- Use bullet points
- Use an uncluttered layout.

Useful Website Addresses

Autism NI

Regional Autistic Spectrum Disorder Network for Northern Ireland

Parents Education as Autism Therapists

Communicating with people living with Dementia

People living with dementia can experience varying degrees of communication difficulty depending on the type of dementia and the stage at which they are in their illness. Difficulties with understanding and expression as well as reading and writing may occur.

Common difficulties include:

- Repeating themselves
- Losing train of thought
- Not understanding what is being said
- Not being able to follow the conversation
- Losing track of the conversation
- Speech sounds unclear or often slurred
- Struggling to find the right word
- Hesitations
- Using the 'wrong' words
- Mixing up the word order in sentences
- A delay in the person being able to process what is being said.

These difficulties can be extremely frustrating for both the person with dementia and those trying to communicate with them. What we must remember is that, even when the ability to verbally communicate is decreasing, a will to connect and communicate remains. The way in which we approach and interact with a person with dementia will have lasting effects for them, whether positive or negative. Although they may not remember what exactly was said to them, the feeling created by the interaction will remain. Therefore it is our responsibility to change how we communicate in order to facilitate positive and effective interactions.

It is vital that we pay close attention to non-verbal communication, especially as the person's verbal communication becomes less reliable. We need to watch facial expressions, gestures and body language as these can give clues as to what the person with dementia may be trying to communicate. Do not simply take a 'yes' to mean 'yes' or a 'no' to mean 'no'. See if the nonverbal cues match up or indicate something else.

Ideas on how to help:

- Face to Face communication
- Reduce distractions and background noise where possible
- One to one interactions are best
- Face the person when talking to them

Communicating with people living with Dementia

- Use short, simple language - stay away from long, complex sentences/stories
- Break up instructions into short steps
- Leave time for the person to process what you have said
- Avoid asking questions where possible
- Use pictures to support your message where possible
- Use gestures and modelling to aid understanding.

Say the person's name to gain attention and regain focus where required.
Do not scold or correct the person with dementia; remember they are the expert!

Telephone Communication

The same principles apply for good communication over the telephone. Be mindful of leaving adequate time for the person with dementia to process what you are saying. Speak slowly and clearly and repeat key words. Ideally, where possible, you should communicate via telephone with a relative or carer as the person with dementia may have difficulty retaining any information passed on to them. If you are changing or giving an appointment for example, it is good practice to support this with an accompanying letter.

Written Communication

Leaflets and written information should be made accessible to people with dementia using simplified language and pictures to support the message where possible. It is important to note that people with dementia may or may not retain the ability to read, and understand what they have read.

Information on the Internet and websites

http://www.alzheimers.org.uk
http://www.dementiacentreni.org

To ensure person-centred care and best practice in dementia care, find out about the life history of the person with dementia. This always helps with how to approach and begin interactions. It is especially important when the person may be feeling unsure or anxious as it can help build rapport and trust. Remember when talking to the person to 'go along' with their reality, as long as it is a happy one. Do not correct or attempt to re-orientate. This will simply serve to decrease wellbeing.

Creating Accessible Written Information

There are some simple rules to follow when creating written documents such as appointment letters and reports, which help to ensure that they are accessible for a wide range of audiences. Bear in mind your audience and their preferred method of communication. The following are examples of how you can communicate more effectively by using RNIB's Clear Print guidelines and through using Easy Read documents.

Clear Print

Clear Print is RNIB's print design guidelines for all types of documents. The guidelines have been specially created to enable everyday information to be immediately accessed by more people.

Who benefits from Clear Print?

Because Clear Print is designed to be used for all documents, it has far reaching benefits. A clearly designed and easy to read document will convey your essential information to everyone who reads it and in the process can convey a positive view of the originating individual or organisation.

Top tips for achieving Clear Print:

- Document text size should be 12-14 point, preferably 14 point
- The font you choose should be clear such Arial and avoiding anything stylised
- All body text should be left aligned
- Use bold sparingly, only highlight a few words rather than a paragraph
- Keep the text layout clear, simple and consistent
- Leading (space between lines) should not be too cramped
- Don't use blocks of capitalised letters, and try not to use any italics or underlining
- Text shouldn't be overlaid on images
- The substrate or coatings should not be glossy or reflective
- Ensure the paper is thick enough to prevent show through
- The contrast between the text and background should be as high as possible
- All text should be the same orientation on the page
- Space between columns of text should be large enough to be distinct
- Any information conveyed in colour or through images should also be described.

For further information about Clear Print see RNIB's See it Right publication.

Creating Accessible Written Information

Easy Read (See Appendix)

Producing information in 'EasyRead' format involves creating the content with Plain English using short, simple, clear sentences with an accompanying image to communicate information. It is particularly useful for people with a learning disability or people with low literacy levels.

Key Points to Remember

- Making information easier is about working with the people your information is for. Ask people with a Learning Disability what they think and if they understand the information
- Consider why you are producing the information
- Consider when the information will be used
- Check what information already exists
- Choose the best format for your information. For example CD or DVD may be better for some people
- Consider providing information in other languages including British Sign Language and Braille
- It is important to remember that people with learning disabilities are a broad group and that often, Easy Reads are public documents, which need to cater for a broad level of ability
- Some people with learning disabilities may also need assistance to go through an Easy Read document
- Easy Read documents can act as a tool for supporters to help someone with a learning disability understand the key issues about a subject.

Quick Checklist

Summary	Is there a clear heading, author, date, reason and summary?
Words	Are the words easy to understand?
Sentences	Are the sentences short and simple?
Images	Do the images make clear what the information is about?
Layout	Is the layout easy to read and understand?

Making your words easier to understand

- Use simple words
- Explain hard words
- Do not use abbreviations
- Be consistent
- Make it personal

Creating Accessible Written Information

- Use full words, not acronyms
- Create a word list at the back of the document to explain hard words.
- Use actual dates and times
- Use a 12 hour clock.

Make your sentences easier to understand

- Talk about 1 idea per sentence
- Keep sentences short and simple
- Each sentence or new idea should be on a new line
- Be friendly
- Use simple punctuation
- Order your information in a logical step-by-step way
- Use active sentences
- Avoid idioms and questions.

Using images to support understanding

- First simplify your language
- Be consistent
- Put a clear picture next to accompanying text
- Make sure images are as big and as clear as possible
- Use an image for each point or chunk of information
- Do not run writing over images
- Images in colour are preferable
- Photographs of real people or places can be really useful
- Use familiar images
- Use the same style of image.

The following page shows an example of a one page document in Easy Read format:

Position images to the left of text.

Write in positive sentences

Avoid negative sentences eg. “walk in the corridor” rather than “do not run in the corridor”. If you have to use a negative sentence try to use “no” rather than using “don’t” or “can’t”.

Creating Accessible Written Information

Please tell us what you think about our communication during your visit to our service today.





Creating Accessible Written Information

Did we show you that they were willing to communicate with you, eg. did we stop what we were doing to talk to you?



no | not often | sometimes | often | always

Did we ask you how best to communicate with you and show that we valued your method of communication?



no | not often | sometimes | often | always

Did we allow enough time to communicate, were we patient?



no | not often | sometimes | often | always

Did we check that you understood?



no | not often | sometimes | often | always

Did we try to have a go at communicating and keep trying?



no | not often | sometimes | often | always

Did we get your attention and look at you when we were talking?



no | not often | sometimes | often | always

Creating Accessible Written Information

Did the environment support your communication. eg. lighting/noise?					
	no	not often	sometimes	often	always

Did we acknowledge your feelings?					
	no	not often	sometimes	often	always

Did we treat you with respect. eg. speak directly to you?					
	no	not often	sometimes	often	always

Did we think about reasonable adjustments to help you today, eg. double appointments, quiet room to wait, providing you with information in advance?					
	no	not often	sometimes	often	always

Case Studies

Case Studies

Here are a few real life examples of service users who have experienced barriers to communication when accessing health and social care. Consider your place of work and think about any potential barriers to access that may exist. What can you, as a staff member of the Trust, do to remove those barriers?

A lady who is deaf visited her GP. Making an appointment was difficult as they could not communicate on the phone. Once in the GP surgery, there was a visual display board to alert patients to their name being called, however the display board was rarely working. The lady had to bring a family member to hear when her name was called. During her consultation, the GP did not speak directly to the lady, and tended to have his head facing towards the computer screen, meaning that this lady could not read his lips and missed a lot of the information. The lady felt that her independence had been removed as she relied on family members to attend appointments and her personal information was being discussed with a third person.

Through raising awareness at this GP practice the patient now feels there has been an improvement and

- The lady can text her request for an appointment
- It is noted on the lady's file that she has a profound hearing loss and she is spoken to directly when being called forward for her appointment with the GP
- The GP speaks clearly, communicating directly with the patient
- The patient feels she has more privacy and independence and she can now choose whether to tell family members about personal issues.

A gentleman who is registered blind and has no perception of light and has experienced the following difficulties in accessing healthcare:

- He has received printed appointment letters in the post from hospitals and also his GP Surgery
- Information has not been written into his hospital notes explaining that this gentleman has two artificial eyes – a nurse handed this patient a mirror and asked him if he would like to look at his face?
- His GP handed the service user an A4 piece of paper explaining his condition and told him to go home and ask one of his family members to read it
- When he was an in-patient at hospital, a Consultant embarrassed him by asking him why he was wearing sun glasses indoors
- The GP surgery is now using a visual display board to alert patients that it is their turn to see the doctor/nurse. There are no audio announcements and this can result in the service user missing appointments.

Case Studies

An adult with a learning disability was feeling very unwell in the middle of the night and was taken by his father to the local Emergency Department. All of the staff in the Emergency Department spoke to the person's father. At no stage did the staff even look at the person with the learning disability. One of the medical staff asked the father how he knew that his son was feeling unwell when he can't speak. There was a complete lack of understanding that speech is not the only method of communication.

Joe is a man with a learning disability and was admitted to hospital for an operation on his foot. During his stay he became incontinent. Staff were unconcerned and did not relate this difficulty to his learning disability. However, his family were very upset and demanded staff investigate why he was now suddenly incontinent. Joe mainly communicates using Makaton signs. He had been asking for the toilet using a Makaton sign but staff did not recognise his communication attempts. The hospital does not endorse the use of signs. Staff are not taught or encouraged to use signing.

Angela is a lady with Motor Neurone Disease who attended a review meeting regarding her care. She uses an Alternative and Augmentative Communication. The professionals attending are very keen to hear from her and to involve her in decision making. They make sure that she is well positioned in the room to take part in the discussion. They also ensure that she has access to a power point in case that is needed. In the review they ask her a number of questions, but when she tries to answer the meeting keeps moving on before she manages to make her response. After 40 minutes the chair of the meeting says they have to finish as the next family are waiting outside for their review. Angela leaves feeling frustrated that her views have not been listened to or taken on board.

Sally has a stammer and rang up to make a dentist appointment but because it can take her some time to start speaking the receptionist hung up. Sally called back and managed to speak before the receptionist hung up. However the receptionist did not give her time to finish her sentences. She interrupted Sally and assumed that she wanted an appointment with the speech therapy service. Sally was very frustrated and tried to correct the misunderstanding but the receptionist would not listen.

Pat has autism and can find waiting difficult and some noises painful. At outpatients he had to wait for a long time in reception. The receptionist did not look very busy but did not explain why there was a delay. There was building work going on which was very noisy. Pat became anxious and distressed he tried to get the receptionist's attention by gesturing and vocalising. Eventually the receptionist told Pat he would have to leave as he was upsetting the other people in reception. Pat felt she was very rude and did not try to help him.

Case Studies

Mary has some difficulty understanding language and reading since her stroke. When she arrived at the health centre she was told by the receptionist to go to the podiatry clinical room 3. Mary did not know the building so asked for directions. The receptionist reluctantly gave directions without looking up; the directions were long and complicated. Mary tried to follow the directions but all the signs were written and she could not read them. She felt very foolish but returned to the reception desk and explained that she could not find the room. The receptionist repeated the same complicated directions speaking very loudly and slowly. Mary again tried to follow the directions but could not identify the room. She finally met another patient who kindly showed her to the room. She was 30 minutes late for her appointment and felt very frustrated.

Gary has dementia and can get anxious going to new places and communicating with new people. He arrived at the reception handing over his appointment letter. The receptionist did not look at the letter but said “name”. Gary was confused as to whether she meant his name or the name of the doctor and hesitated. The receptionist ignored him and turned to his brother asking what is his name and what was wrong with him. Gary was angry and frustrated that he was being ignored. He did not like to be talked about. He felt like the receptionist thought he was drunk or daft.

Brenda has a progressive neurological condition which makes her speech unclear and affects her movements. She rang her doctor to make an appointment, and due to her unclear speech this took a long time. After she had hung up she realised she could not read the date or time due to her difficulties with handwriting. She called back to ask the receptionist to repeat the date and time of the appointment. Brenda felt the receptionist was inpatient and rude and thought that Brenda was drunk. It would be easier for Brenda to make appointments online and have the appointment sent to her phone via text alert.

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Health and Social Care Board

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Stroke Association

BHSCT Sensory Support Team

BHSCT Speech Therapists

Cedar Foundation

RNIB

Disability Action

Mencap

Deafblind NI

Cedar Foundation

BHSCT ASD Service User's Forum

SHSCT Sensory Support Team

Northern Ireland Speech and Language Therapy Acquired Brain Injury Forum

HSC Trust Equality Leads.

Appendix: Easy Read Guide

What is Easy Read?



People with learning disabilities can find it harder to understand things and to learn new things. This is why it is important for people with learning disabilities to have information that is as clear and as easy to understand as possible. Good information helps people find out what they need to know. It helps them to make their own choices and If people with learning disabilities do not get good information, they will be left out. They will not be able to join in with things happening around them. And they will have to wait for other people to make choices and decisions for them. To make good information means making information easy to read and understand. To do this well, you have to follow standards. (Europe)

Easy Read is an essential tool designed to make complicated text easy to understand and can help make information accessible. It's designed for people with learning disabilities or those who struggle to read. Easy read information contains only the main information using easy words and short sentences that are jargon free. The information is usually presented in the order that makes most sense with big, clear pictures or symbols relating to the information. Hard words are explained in coloured boxes or on a hard words page. People with learning disabilities are the experts in knowing whether information is easy to read and understand. No easy to read text should ever be written without people with learning disabilities taking part at some point.

Easy Read is not a simple translation of existing documents. Writing easy-to-read texts takes time and skill. You have to check a lot of things to make sure that people with learning disabilities will be able to read it.
"Making information easier to understand for people with learning difficulties is about more than making your text size bigger and putting some symbols or pictures in your document. It's about working with people your information is for, finding out together how you can make the information useful and accessible for them. It's about thinking about how we all make sense of information. There are no quick answers, and it isn't easy... but it can be fun." (Health, revised 2010)

Many excellent easy read resources are available and often services can adapt existing resources for example www.easyhealth.org.uk.

Remember Easy Read will not work for everyone and should be considered alongside other accessible information and communication tools.

Appendix: Easy Read Guide

Why is Easy Read important?

Like everyone else, people with learning disabilities have a right to good information. This is written in the Convention of the United Nations which is about the rights of disabled people. In its article 9, this Convention says that people with disabilities have to receive accessible information. In the general population 79% of adults have “recognised” literacy skills. This means that more than 1 in 5 do not have “an ability to read”. Within the population of people with learning disabilities, between 5% and 10% of adults have “recognised” literacy skills. This means there is a high need to provide information in an accessible way. When information is provided in a written form there needs to be effort to make this easy read.

The National Patient Safety Agency highlighted the lack of accessible information as a leading cause of early death. The safety of adults with Learning Disability can be improved with accessible information.

Creating Easy Read information also saves time and money. The biggest waste of time and money is creating information people cannot use. You waste the cost of creating the document as it doesn’t provide the information it is intended to give. You also waste the costs of paying workers to support people to understand the information. The Plain English Campaign estimates it has saved the British Government £500 million in the last two decades. Royal Mail saved £500,000 in nine months by changing one form. So by making information accessible, you actually save time and money!

Easy Read information can help to empower people. It means they can;

- Know what is going on
- Get involved
- Have their voice heard
- Improve services for themselves and for other people
- Claim their rights.

These Easy Read guidelines are a quick summary of the most recent good practice and recommendations for easy-read, including:

Department of Health’s Guidance, 2010 Revision

http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215923/dh_121927.pdf

Information for all - European Standards for Making Information Easy to Read and Understand

http://www.inclusion-europe.org/etr/en/european-easy-to-read-standards
http://inclusion-europe.org/images/stories/documents/Project_Pathways1/Methodology.pdf

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