Appendix E - Good Examples of Communication Information in Full: August 2024

Respectful and inclusive language and communication in Health and Social Care

Respectful and inclusive language and communication in Health and Social Care a sub-group of the Supported Living Network

Housing matters
Supporting well
Supported Living
Improvement Network
Regulating well

Words that may be hard to understand	
	**Communicate** and **communication** means how we share information with other people. For example, **talking** and **writing** are ways to share information or **communicate** with other people.
	**Label** A **label** is a name that we use to describe some groups of people. For example • A wheelchair user • Adult with Challenging Behaviour • An Epileptic.
	**Stigmatize** To **stigmatize** means to treat someone or something unfairly by disapproving of them. For example Labels should not define a person; they take away from the person and focuses on the disability.

Appendix E – Good Examples of Communication Information in Full

The Language of Respect By Laura Mole Chapman May 10th, 2012

What is the importance of respectful language in nursing?
Respectful language makes communication more effective in many ways, since it prevents misunderstandings and conflicts. It also reassures patients that you see them as people who have personal and social needs as well as medical needs. Respectful language shows attention, uses descriptive words and is problem-oriented.

I started my research into ‘respectful language’ having delivered a number of workshops on the subject as part of Equality and Diversity programmes. People often requested this session because in their professional roles they felt scared to use ‘wrong words’. What always struck me was that during the training activity people often expressed frustration with political correctness, it made them angry or more confused about what to say. Often people were happily surprised to find out that some of the ideas that underpin respectful language come from the Civil Rights movement. Unlike political correctness, respectful language demands an intentional and deliberate understanding from the speaker to recognise phrases that denote group stereotypes or ‘characteristics’ under the law (Equalities Act UK).

The use of respectful language, therefore, encourages people to take responsibility for what they say and think about the impact of the ideas behind their words. Particularly at work, professionals have a duty to remove the discrimination some groups face, with that comes a need to learn about language ownership and group identity. Using a research methodology that also respects the principles of Asset-Based Community Development, the interviews gave people opportunity for a dialogue that supports reflection for action.

The development of respectful language is one way of engaging an entire community of practice in cultural change. The purpose is not to identify ‘good’ or ‘bad’ words in order to define correct terminology once and for all. It is about a shared authority, in this context, leadership activity may be viewed as conversations between individuals from different groups to increase awareness of different experience.

Five things I learned from this research:

1. **Community:** ‘A community of practice’ can be defined as a willing association of professionals, a diverse group working across institutions. There is a danger in the assumption that marginalised groups exist outside these typical social networks. Therefore working with a community approach makes entitlement clear – stating an expected sense belonging. A statement against the segregation, that can fragment groups and threaten relationships within communities.

2. **Respect:** is a demonstration of empathy, a mindful and proactive activity. Empathy requires intentional thinking, the recognition that other people’s feelings and circumstances are separate from our own, and a willingness to act appropriately in response to these. Respectful language, therefore, begins with

an intention to respond to what others actually want. Showing respect does not involve benevolence or guess work, or simply giving what we are comfortable with having identified as a need – it is a conversation.

3. **Reflection for action:** Stereotypes tend to fit with our existing worldview, so addressing our own thinking requires an external – participation in a different experience. An understanding of our learning may secure a better judgement, but in conversations with others we gain different insights, feelings and perspectives that could lead to different understanding.
4. **Leadership:** requires confidence, helping others learn is a generous act, as a Leader a teacher is acting to prove their own worth but enabling others to grow theirs.
5. **Professionalism:** is about collective ideas, the co-construction of knowledge and the development of joint purpose. This is achieved through the process of creating a common language, one that reflects and affirms shared principles and equal humanity.

These findings demonstrate the asset-mapping of a worldwide community of practice and these ideas the gifts of professionals who gave their time so generously. Our conversations taught me we belonged to the same web of activity, a network of people who care deeply enough to express their commitment through daily activity that helps secure change to make shared vision a reality.

Full Article: https://legacycultures.com/the-language-of-respect/

Respectful Disability Language: Here's What's Up!

"The difference between the right word and the almost-right word is the difference between lightning and a lightning bug." By Mark Twain

What does "Respectful Disability Language" Mean?
The Disability Rights Movement advocates for positive changes in society. These changes include equal rights under the law and equal access to housing and employment. It could also mean improving how people with disabilities are talked about in places like the media or in everyday conversations. The use of language and words describing people with disabilities has changed over time. It's important that people are aware of the meaning behind the words they use when talking to, referring to, or working with the Disability Community. Disrespectful language can make people feel excluded and can be a barrier to full participation. This is a guide to using respectful words and language.

When does Language = Power?

Imagine living your whole life always having to explain why the words that people use are hurtful and offensive to you. Teachers, co-workers, friends, and family need to know how the words and phrases they use make you feel. Many of us are brought up in homes in which we are the only one with a disability. Maybe we haven’t learned to think of ourselves or other people with disabilities as proud individuals. People with disabilities want respect and acceptance. Many people who do not have a disability now will have one in the future. Others will have a family member or a friend who will become disabled. If you become disabled in your lifetime, how do you want people to describe you? If a family member or friend becomes disabled, how would you want him/her to be treated? Disability affects all people. So learn respectful language and teach others.

General Guidelines for Talking about Disability

- Refer to a person's disability only when it is related to what you are talking about. For example, don’t ask “What’s wrong with you?” Don’t refer to people in general or generic terms such as “the girl in the wheelchair.”
- When talking about places with accommodations for people with disabilities, use the term “accessible” rather than “disabled” or “handicapped.” For example, refer to an “accessible” parking space rather than a “disabled” or “handicapped” parking space or “an accessible bathroom stall” rather than “a handicapped bathroom stall.”
- Use the term “disability,” and take the following terms out of your vocabulary when talking about or talking to people with disabilities. Don’t use the terms “handicapped,” “differently-abled,” “cripple,” “crippled,” “victim,” “retarded,” “stricken,” “poor,” “unfortunate,” or “special needs.”
- Just because someone has a disability, it doesn’t mean he/she is “courageous,” “brave,” “special,” or “superhuman.” People with disabilities are the same as everyone else. It is not unusual for someone with a disability to have talents, skills, and abilities.
- It is okay to use words or phrases such as “disabled,” “disability,” or “people with disabilities” when talking about disability issues. Ask the people you are with which term they prefer if they have a disability.
- When talking about people without disabilities, it is okay to say “people without disabilities.” But do not refer to them as “normal” or “healthy.” These terms can make people with disabilities feel as though there is something wrong with them and that they are “abnormal.”
- When in doubt, call a person with a disability by his/her name.

Words to Describe Different Disabilities

Here are some ways that people with disabilities are described. This list includes “outdated language” – terms and phrases that should not be used. This list also includes respectful words that should be used to describe different disabilities. What is “okay” for some people is not “okay” for others. If you don’t know what to say, just ask how a person likes to be described.

Disability	Out-Dated Language	Respectful Language
Blind or Visually Impairment	Dumb, Invalid	Blind/Visually Impaired, Person who is blind/visually impaired
Deaf or Hearing Impairment	Invalid, Deaf-and-Dumb, Deaf-Mute	Deaf or Hard-of-hearing, Person who is deaf or hard of hearing
Speech/Communication Disability	Dumb, “One who talks bad"	Person with a speech / communication disability
Learning Disability	Retarded, Slow, Brain-Damaged, “Special ed”	Learning disability, Cognitive disability, Person with a learning or cognitive disability
Mental Health Disability	Hyper-sensitive, Psycho, Crazy, Insane, Wacko, Nuts	Person with a psychiatric disability, Person with a mental health disability
Mobility/Physical Disability	Handicapped, Physically Challenged, “Special,” Deformed, Cripple, Gimp, Spastic, Spaz, Wheelchair-bound, Lame	Wheelchair user, Physically disabled, Person with a mobility or physical disability
Emotional Disability	Emotionally disturbed	Emotionally disabled, Person with an emotional disability
Cognitive Disability	Retard, Mentally retarded, “Special ed”	Cognitively/Developmentally disabled, Person with a cognitive/developmental disability
Short Stature, Little Person	Dwarf, Midget	Someone of short stature, Little Person
Health Conditions	Victim, Someone “stricken with” a disability (i.e. “someone stricken with cancer” or “an AIDS victim”)	Survivor, Someone “living with” a specific disability (i.e. “someone living with cancer or AIDS”)

Full Article: https://systems.aucd.org/docs/add/sa_summits/Language%20Doc.pdf

Communication skills in social care

Communication is all about making contact with others and being understood. This guide will give you tips on how to communicate with the people you work with. It includes specific help when communicating with people with autism, dementia and hearing impairments.

Good communication skills will help you:

- develop working relationships
- Provide clear information.
- give and receive information about the care and support you are providing
- provide emotional support to the people you work with
- carry out an assessment of an individual’s care needs

The Importance of Meeting Communication Needs

Communication impairments commonly associated with learning disabilities and autism are expressive communication and comprehension. It is likely therefore that you will have to adapt your communication methods accordingly.

Effective communication is essential when providing information about care and treatment to ensure that the patient can give informed consent. You can help by following this guidance:

- Use simple language and keep your sentences short.
- Explain any difficult or unfamiliar words. For example: Instead of “I will send you for an x-ray” it may be better to say “we will need to take a picture of your arm”.
- Check that the individual has understood: “Can you please tell me in your own words what I have just said”.
- Give the person time to respond.
- Use gestures to emphasise your communication. For example, point to the part of the body you are talking about.
- Use pictures or objects to demonstrate what you are going to do before you do it.
- Consider what ‘Easy Read’ information may be available.
- Be aware of any additional disabilities such as hearing or visual impairment.
- Using a number of communication methods together to support people with complex needs is known as ’total communication’. This might include a mixture of speech, gesture and accessible written information or pictures. This is the most effective method for providing effective communication.

Communication skills in social care	
	Easy Read For some people with a learning disability it is helpful if information is provided in an easy read format or picture story boards. There are a number of useful Easy Read documents available online, some examples: http://www.easyhealth.org.uk https://www.changepeople.org/ https://www.accessibilityeasy.com/blog/finding-photos-for-easy-read https://www.england.nhs.uk/learning-disabilities/about/resources/er/ https://www.learningdisabilities.org.uk/learning-disabilities/our-work/health-well-being/easy-read https://be.macmillan.org.uk/be/s-428-easy-read-titles.aspx You can also contact the Specialist Nurse for Learning Disability and Autism if you would like support to provide Easy Read information for your patients.

Communicating with someone with dementia

Dementia will gradually affect the way a person communicates. Their ability to present rational ideas and to reason clearly will change.

- Speak at a slightly slower page, allowing plenty of time to allow the person to process what you've said and respond.
- Avoid speaking sharply or raising your voice as this may cause distress.
- Don't talk as if the person isn't there or like a child. Show respect and patience and always involve them in the communication.
- Using humour can sometimes ease a situation – for example if someone gets the wrong end of the stick or makes a mistake.
- Avoid asking direct questions. Someone with dementia could become frustrated if they can't find the answer.
- Ask questions one at a time.
- Don't ask complicated questions. Whilst choice is important, too many options can be confusing.
- If they don't understand, use objects, images or hand movements to help explain.
- Someone with dementia might get confused between what has and hasn't happened, for example eating lunch or having a shower. Use your judgement to respond.

Full Article: https://www.nhs.uk/conditions/dementia/living-with-dementia/communication/

Common Core Principles for Supporting People with Dementia

A guide to training the social care and health workforce

Full Article: https://www.skillsforcare.org.uk/resources/documents/Developing-your-workforce/Care-topics/Dementia/Common-core-principles-for-supporting-people-with-dementia.pdf

Understanding and developing communication with someone with autism

Most autistic people experience difficulty with:

- interacting with others
- initiating interactions, responding to others, or using interaction to show people things or to be sociable
- understanding and relating to other people
- taking part in everyday family, school, work and social life. These can be harder.

Full Article: https://www.autism.org.uk/advice-and-guidance/topics/communication/understanding-and-developing-communication

Getting and keeping their attention

- Always use their name at the beginning so that they know you are talking to them.
- Make sure they are paying attention before you ask a question or give an instruction. The signs that someone is paying attention will be different for different people.
- Use their hobbies and interests, or the activity they are currently doing, to engage them.

Processing information

An autistic person can find it difficult to filter out the less important information. If there is too much information, it can lead to ‘overload’, where no further information can be processed. To help:

- say less and say it slowly
- use specific key words, repeating and stressing them
- pause between words and phrases to give the person time to process what you’ve said, and to give them a chance to think of a response
- don’t use too many questions
- use less non-verbal communication (eg eye contact, facial expressions, gestures, body language)
- use visual supports (eg symbols, timetables, Social Stories) if appropriate
- be aware of the environment (noisy/crowded) that you are in. Sensory differences may be affecting how much someone can process.

Full Article: https://www.autism.org.uk/advice-and-guidance/topics/communication/tips

Engagement and communication

Communication can be difficult for some autistic people. They may have difficulties initiating interactions or responding to others. Processing time is often affected so it may take an autistic individual longer to react to conversation.

Every autistic person will have their own preferred method of communication. They may communicate vocally, or they may use other systems such as sign or a voice output communication device (VOCA). Here are some simple things you can do to support them:

- Observe how the person chooses to interact and how long it takes them to process what you are saying or doing. You can then adjust your communication. You might need to:
- Use their name to make sure they know you are talking to them directly
- Make sure any instructions are short and clear to avoid overloading with information
- Be mindful of noisy environments as this may affect how a person processes information
- Avoid using figurative language

- Talk slowly so they have more time to process
- Avoid asking open-ended questions, be clear on what you are asking
- Use visuals. If the person you are talking to finds visuals easier to understand, try to use where possible

Behaviour is a form of communication.

Therefore, autistic people may display different behaviours to try to communicate their needs, wants or feelings. Some of these behaviours can be perceived as challenging and may affect their wellbeing or that of those around them. Understanding why these behaviours occur is an important step to helping to find alternative and more effective means of communication.

Full Article: https://www.beyondautism.org.uk/about-autism/understanding-autism/engagement-and-communication/

Communicating with someone with autism

People with autism have very varied ways of communicating. Until you know an individual's own way of communicating here are some general tips to keep in mind.

- People with autism may find it difficult to read social cues and body language. Use clear language and don't show frustration if you feel someone should know something already, or if they ask questions which seem repetitive.
- People with autism might take language very literally so try to use language precisely; for example saying "wash your hands in the sink" not "wash your hands in the toilet".
- People with autism might miss non-verbal cues so ensure your communication is as clear as possible For example when you are leaving actually say 'I need to pack up ready to leave' rather than starting to pack up.
- Don't assume that someone with autism is ignoring you if they don't make eye contact. Some people can find this uncomfortable or unnecessary – some people learn to make eye contact to fit in but might be able to listen to you better if they don't.
- If you need to ask the adult a question, try to make the question as specific as possible. Broad, generalised, and vague questions are hard for autistic people to answer and can trigger anxiety.
- People with autism can be more or less sensitive than usual to senses like smells, noises, light or temperature. Be aware that this may interfere with their concentration and communication.
- Some people with autism have routines that are very important to them and disrupting their routines will make it harder to communicate with you.
- Many people with autism experience anxiety which they may hide or not know how to communicate – when anxious a person may not be able to hear what you are saying so keep communications simple and to the point.
- Sharing interests can be a good stimulant for conversation. Find something you have in common or be prepared to really listen to the person's special interests – that way you will learn more about what matters to them and show them you care.

Communication with someone with a learning disability

Difficulty understanding abstract concepts

People who have a learning disabilities/autism are likely to have difficulty understanding abstract concepts or have limited understanding of the treatments being proposed. Showing the person before you do the procedure can help alleviate anxiety. Many individuals will require such preparation and information in order to make an informed decision and to consent to treatment. It is likely that any intervention will take longer to complete. Remember that, giving time and communicating effectively will improve that experience for the patient.

Relationship

Developing a relationship is vital when the person is anxious. It is sometimes helpful to have two people attending to the person, one to provide reassurance and distraction and the other to complete whatever intervention is needed.

Keep your head up and be at the person’s level

Talk to the person – not their support worker. Give them your full attention. Gain their attention. This will help the person to know you are talking to them and help you judge whether they understand Try not to look at notes or a computer screen. Make sure the person can see you clearly and can see your hands and mouth in case they use lip reading or gestures to help them.

Speak clearly and use easy everyday words and sentences

People with learning disabilities have difficulties understanding spoken language. Communication partners often overestimate the understanding of people with learning disabilities, and make their language too complicated. This puts too many demands on the person, who may withdraw, show challenging behaviour, or fail to do what is asked. Speak slowly, clearly and use everyday vocabulary.

Take time

Give enough time for the person to listen, process, understand and think of an answer. Some people with learning disabilities take longer to process what you are saying. Others may find physical movement or speech effortful, so it takes them longer to respond. Remember many people with learning disabilities have unidentified health needs that may affect their communication (hearing, vision, epilepsy, pain, physical difficulties, medication).

Use visual cues to support understanding

Supporting your spoken language using visual cues such as pictures, objects and gestures is very important. This means drawing what you are talking about, pointing to what you are discussing or show objects and where possible demonstrating how they work. People with learning disabilities like to use other ways to help them understand spoken language. Visual cues may increase the person’s chance of understanding what you are saying to them.

Give information a bit at a time

Use short sentences. Two or three key words in a sentence are often enough. Do not give large amounts of information at once. Break this into smaller chunks and give time for people to listen and understand.

Accept and know the way people communicate

People with learning disabilities use a range of means to express themselves. Some speak but may not be able to use complex language. Some use non-verbal communication such as pointing at pictures, gestures, signs, objects, symbols or communication aids (such as voice output devices). Some people prefer symbols, others colour photos. Some may use informal communication such as facial expression, eye gaze or body language.

Respect a person's way of communicating by using it to them (e.g. if they sign make sure you can or that there is someone with them who can: if they have a communication book/aids make sure it is available to the person and use it to give information).

Do not ask too many questions

People with learning disabilities find questions hard. Try and get them to tell you things. If you ask lots of yes/no questions, they will probably answer you but not necessarily understand what you said.

Check out understanding

People with learning disabilities may appear to understand because they are good at responding to facial expression, body language, tone of voice or other cues. They may misunderstand, forget or not catch some of what you say. They may answer "yes", even if they do not fully understand. They may not be able to contradict you if you have misunderstood what they mean or want. They may not let you know they don’t understand. Recap all information you have given. Summarise and write it down if that will help.

Ask for help – there is no substitute for knowing a person well

Check that **you** have understood. Talk to others. Help the person to tell you if you have misunderstood them. Don’t pretend you can understand if you really can’t!

If you continue to have difficulty communicating with the person, ask people who know them or refer for speech and language therapy.

Communicating with someone with a hearing impairment

- Body position is important. Make sure you are facing the person and they can see your mouth.
- Speak clearly, slowly and distinctly – do not shout as this might distort communication and make it harder to lip read

- Ensure you have the person's attention before you start talking. You could this be saying their name or tapping their arm.
- Avoid long, complex sentences. Keep them short and clear.
- Try to minimise background noise as this may interfere with hearing aids. There are aids you could use to communicate with people with a hearing impairment.
- Hearing aids – Hearing aids can support you to hear every day sounds such as the doorbell or TV, and other people talking. You can find out more about hearing aids at http://www.nhs.uk/Livewell/hearing-problems/Pages/hearing-aids.aspx
- Hearing loss is common, particularly as you get older. See a GP if you have problems with your hearing. It could be caused by something that can be easily treated. You can find out more about hearing aids at https://www.nhs.uk/conditions/hearing-loss/
- Hearing aids and implants, a GP can help you get hearing aids if you think you need them. You can find out more about hearing aids at

  https://www.nhs.uk/conditions/hearing-aids-and-implants/

  http://www.nhs.uk/Livewell/hearing-problems/Pages/hearing-aids.aspx
- A hearing loop is a sound system for people with hearing impairments. A microphone and amplifier are connected by a loop cable to aid hearing. You can find out more about hearing aids at http://www.ageukhearingaids.co.uk/hearing-aid-news/what-hearing-loop-system
- Visual aids – visual aids can support communication and make things easier to understand. They can be used in different ways to support people. You could:
- use white boards to communicate with someone with a hearing impairment
- use images of food instead of a written menu
- make a calendar with pictures for different tasks such as a doctor's appointment or a day trip out
- Make a flip book with common phrases, emotions or objects on as a pocket reference for people with a hearing impairment.
- Sign language – sign language is a visual means of communicating using gestures, facial expression and body language. You can find out more at http://www.british-sign.co.uk/

Communication support Nottinghamshire Healthcare Trust offer

Talk to the person – not their support worker. Give them your full attention. Gain their attention. This will help the person to know you are talking to them and help you judge whether they understand.

https://www.nottinghamshirehealthcare.nhs.uk/cslt-communication-support

Five Good Communication Standards

Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings, produced by the Royal College of Speech and Language Therapists.

https://www.rcslt.org/wp-content/uploads/media/Project/RCSLT/good-comm-standards.pdf

https://www.rcslt.org/wp-content/uploads/media/Project/RCSLT/5-good-comms-standards-easy-read.pdf

Communication problems after a stroke

This guide is for anyone supporting a stroke survivor with communication problems.

A stroke can cause mental and physical impairments, and make communicating with someone difficult.

The person who has had the stroke may find it hard to form words or understand what you say to them. This may make it difficult for you to work out what they want.

If the person has problems with speech, language, writing or swallowing, they can be referred for speech and language therapy to help them regain those skills.

When you communicate with someone who is recovering from a stroke, it's important to give them your full attention and try to avoid any background distractions. Try to speak clearly and at a normal volume.

Make sure you're listening and watching for the person's reactions, as not all communication is verbal. It's also important that you don't pretend you've understood them if you haven't. Don't try to speak for them.

Full Article: https://www.stroke.org.uk/communication_problems_after_stroke_guide.pdf

Full Article: https://www.nhs.uk/conditions/social-care-and-support-guide/practical-tips-if-you-care-for-someone/how-to-care-for-someone-with-communication-difficulties/

How to care for someone with communication difficulties

The adult or child you're caring for may find it difficult to communicate because of a physical health problem – such as a hearing difficulty, a problem with their eyesight or a developmental disorder – or because of a disorder affecting their brain, such as Alzheimer's disease or stroke.

Communication problems can come on gradually or happen overnight. If they're sudden, you will need to re-evaluate how you communicate with the person you care for.

Consider your tone of voice, how quickly you speak, and how you use body language and gestures to emphasise what you are saying. Find out what helps them or makes your communication clearer.

Someone who has a physical or mental illness or disability may be affected by your own and other people's reactions to their condition. This could change their ability to communicate.

Types of communication problems

Speech problems can happen for no clear reason or because of a:

- stammer
- cleft palate
- brain injury
- hearing problem

Language disorders

Language disorders are problems understanding or using words. They can be triggered by a stroke or brain injury.

Children learn to talk by listening to the people around them, and mimicking sounds and mouth shapes. It helps to talk to your child, and encourage sounds and speech from an early age. If their progress seems to be delayed, take them to a doctor for a check-up.

Some people grow out of these disorders during childhood, while others live with them throughout their adult life.

Speech and language therapy can help, particularly in younger people. You can access this through your child's special educational needs co-ordinator or a GP.

Selective mutism

Selective mutism, sometimes described as a "phobia of talking", is an anxiety disorder that stops children speaking in certain social situations, such as in school lessons or in public.

However, they're able to speak freely to close family and friends when nobody else is listening – at home, for example.

If your child is selectively mute, be patient. Don't put pressure on them or bribe them to speak.

Find out more about selective mutism.

Deaf blindness

Deafblind people have a sight and hearing impairment. Some people are born deafblind, while others become deafblind in later life through an accident or old age.

People who are deafblind may not use words, and it can be difficult to work out the best way to communicate with them.

Find out more about deaf blindness.

The charity Sense supports and campaigns for children and adults who are deafblind.

Full Article: https://www.nhs.uk/conditions/social-care-and-support-guide/practical-tips-if-you-care-for-someone/how-to-care-for-someone-with-communication-difficulties/

What communication skills does a care worker need?

Care workers need a select set of skills to be successful when communicating. These develop during their time in care, but must always be present in their role. Some examples include:

- To be able to organise a conversation and keep it going, to draw out all the information they need from a service user as they can come across barriers.
- Have good listening skills so they can check understanding with the person.
- Using non-verbal communication is key. There may be times the service user struggles verbally. Understanding their requirement without the need to be verbal and making sure they understand is important for their treatment.

- ask questions
- Understand cultural differences and how they might impact communication.
- understand how disability and physical and mental conditions might impact

These skills should come naturally to a care worker as along with their core English, number and general employee skills, they need to have natural empathy and be a ‘people person’ which is something a lot of residents require in their day-to-day lives in care.

You can find out more at https://www.skillsforcare.org.uk/resources/documents/Developing-your-workforce/Care-Certificate/Care-Certificate-Standards/Standard-6.pdf

How do we communicate effectively - Verbal communication

Verbal communication is the use of words and sounds to share information with others.

Communication goes two ways. Giving and receiving messages requires consideration of both the carer and service user to make it effective.

The Cycle of Communication (below) is key to this and is the process of the sending, receiving and decoding of messages. Now, this does not mean you are going to have to start learning Morse code. The Cycle is totally applicable to the kind of verbal communication that is going on all the time in care, especially with people who may have diminished communication skills, dementia, or difficulty expressing themselves.

This theory of effective communication was first developed by Charles Berner in 1965 and is when someone decides to communicate. The process involves taking action (message sent), which is then received by the other person (message received). This person then works out the meaning (message decoded) and lets the other person know they have understood (feedback). The feedback is the response to the message and then the whole cycle may start again.

With this there are various factors to consider when promoting communication between service users and workers.

In a care setting it’s important to think about the needs of the service user, since this is the core part of the care workers’ job role. Not all service users are the same, so the purpose of the communication is to establish what the individual requires.

Think about what you’re saying

- First impressions count – saying hello and goodbye are an important way of gaining someone’s trust before a conversation.
- Give accurate information – when someone is given inaccurate information or poor explanation, it can often be confusing and hinder understanding.
  Ensure you give the person you are supporting all the information they need.
  If you don’t have this, find out the answer and come back to them as soon as possible.

- Use open questions – they give people the chance to talk rather than give one word answers. For example you could ask ‘How are you?’ rather than ‘are you ok?’
- Repeating and rephrasing - these are strategies that can help some people to understand what is being said to them.
- Avoid jargon, slang and acronyms – these will only make sense to people with specialist knowledge. A person without this knowledge won’t understand what you mean.

Tone and pace

- Speak clearly and slowly – this will help people to understand what you’re saying. Mumbling and talking too quickly can lead to misunderstandings.
  Speaking a little more slowly can help a person with a hearing or visual impairment, a learning disability or who is confused.
- Allow time for the person to respond. This can mean allowing silences while the person thinks and works out how to reply.

Clarify messages

It is important to show you understand what the other person is saying. You could summarise what they are saying to check your understanding. For example ‘so just to check, you meant that …’

Be an active listener

Active listening involves paying attention to what the other person is saying. To acknowledge that you are engaged in the conversation you can nod your head, make ‘mmm’ sounds and use encouraging words such as ‘yes’ and ‘I see’.

Showing empathy when communicating

Empathy lets a person know that you understand how they feel and think. You can show this by using the same techniques as active listening.

Non-verbal communication

There are lots of ways we communicate that aren’t verbal. We use our eyes, facial expression, hand and arm gestures and the way we sit and stand to communicate.

Eyes and eye contact can indicate feelings.

- Short or broken eye contact can express nervousness, shyness or mistrust.
- Long unbroken eye contact can express interest. If you are listening to someone, this can show you are paying attention to what they’re saying.
- Making eye contact can be a way of building a connection with someone.

Facial expressions

Movements of the face can indicate how a person is feeling and allow you to express how you feel when communicating with someone.

- Smiling can mean someone is happy, feels comfortable in the situation or is excited.
- Frowning can mean someone is unhappy.
- A tense facial expression can mean someone is sad.
- Wide eyes can mean someone is excited or interested.
- Looking away can mean someone is bored or uninterested.
- A scrunched up head and nose and pursed lips could mean someone is confused.

Posture

The way we sit and stand can express feelings.

- Crossed arms could mean someone is bored, uninterested or angry.
- Leaning forward can mean someone is interested and involved.

Proximity

Proximity involves the physical closeness between people when communicating.

- Being physically close to someone may be reassuring and may be seen as accepting the person.
- Getting too close might make the person feel uncomfortable and threatened.
- Being too far away could indicate someone may feel isolated or uncomfortable.
- People need less personal space when they have a close, trusting relationship.
- Judge how the other person reacts – if they appear agitated, you may be too close.
- Standing at a slight angle can show you are relaxed and friendly.
- When communicating, you should move your proximity in response to the other person’s body language. You could also ask questions such as ‘Do you mind if I sit here?’

Environment

The environment can affect how well people communicate.

- Noise – this can affect someone’s ability to listen and concentrate. To improve communication you could sound proof rooms, reduce background noise or create quiet areas specifically for talking.
- Lighting – poor lighting can mean you can’t see non-verbal communication features such as eye contact or body language. When communicating with someone, make sure you are facing the light so the other person can see your face, particularly your mouth.
- Privacy – a lack of privacy may cause discomfort and discourage people from expressing their true feelings. Try to avoid sensitive conversations in groups and be subtle when talking about something that might cause embarrassment.

What communication skills does a care worker need?

The Care Certificate Communication

Good communication develops your knowledge and understanding about individuals and the part played by other workers so that the best care and support possible can be provided.

Different people have different ways of communicating that work best for them. Some of the different types of communication are:

- Verbal communication - Differences in how you speak, including the tone, pitch, speed and volume of your voice could change how your messages are taken in. Try to avoid using jargon or abbreviations and complicated words and terminology. Make sure you always speak in a respectful way, adjusting your speech to suit the individual.
- Sign language - This is a recognised language throughout the world. British Sign Language (BSL) is used by individuals in this country and there are variations of sign language in different regions.
- Makaton - This is a form of language that uses a large collection of signs and symbols. It is often used with those who have learning and physical disabilities, or hearing impairment.
- Braille - Is a code of raised dots that are ‘read’ using touch. For people who are visually impaired or who are blind, the system supports reading and writing.
- Body language – This is a type of nonverbal communication. There are many different aspects of body language, including gestures, facial expressions, eye contact, body positioning and body movements. Each of these will communicate information about an individual or a worker often without them realising it.
- Gestures – These are hand or arm movements that emphasise what is being said or used as an alternative to speaking.
- Facial expressions – These support what is being said by showing reactions or feelings. They can give you valuable clues that you can use to check out a person’s feelings.
- Eye contact - Maintaining good eye contact is an important way for a worker to show that they are engaged and listening.
- Position - The way that we stand, sit or hold our arms when we are talking will
- provide others with clues about our feelings, attitude and emotions.
- Written communication - This method is used to send messages, keep records, or provide evidence.

https://www.skillsforcare.org.uk/resources/documents/Developing-your-workforce/Care-Certificate/Care-Certificate-Standards/Standard-6.pdf

Non-Verbal Communication

Non-verbal communication is as important as verbal in interactions that influence dignity. For example, in a study of older people’s transitions (include older people with learning disabilities) between care service, Ellins et al. (2012) noted the following:

‘One of the most striking findings was that even the smallest gestures by providers to connect with somebody as a human being, such as a smile or a hug could make

Sign language

Sign language is a way of communicating visually, using hand gestures, facial expressions and body language. There are hundreds of different types of sign language in use across the world.

British Sign Language

British Sign Language (BSL) is the sign language used by deaf people in the UK. BSL uses hand gestures, finger spelling, lip patterns and facial expressions.

Full Article: https://royaldeaf.org.uk/what-is-bsl/

Sign Supported English

Sign Supported English (SSE) is a variation of BSL. It uses BSL signs, but the structure and grammar are based on spoken English. This means the signs follow the exact order they would be spoken in.

SSE doesn't require any knowledge of BSL grammar structure, so is easier for hearing people to learn. It's often used in schools where deaf children are taught alongside hearing children.

Full Article: Sign Supported English (SSE) | Information for deaf children and young people (ndcs.org.uk)

Deafblind Manual - Tactile signing

Some deafblind people prefer to use tactile signing, such as the deafblind manual alphabet and Block, where words are spelled out on the individual's hand.

Showes pictures of some of the Deafblind Manual alphabet signs, with simple instructions. Practise these and the other signs every day for 10 minutes and you'll pick it up in no time.

Full Article: https://www.sense.org.uk/information-and-advice/ways-of-communicating/deafblind-manual/

Makaton

Makaton is used by adults and children with learning disabilities and communication problems. It uses a combination of picture symbols and hand gestures that are similar to BSL and speech. Many people with learning disabilities use speech, there are also a range of alternative methods of communication which can be used in conjunction with speech. Sign systems are used widely among people with learning disabilities, either alone or in conjunction with speech.

In addition to children and adults with communication and learning difficulties and the community around them – for example, teachers, health professionals, friends, public service bodies etc. Makaton is increasingly used by the general public to aid communication.

Makaton has been shown to be useful for all sorts of people including those who struggle with understanding concepts, those who have poor literacy skills, including grammatical knowledge, and those with English as an Additional Language. By using Makaton, children and adults can take a more active part in life, because communication and language are the key to everything we do and learn.

https://www.makaton.org/TMC/AboutMakaton.aspx?hkey=c8a4263d-78cc-4c30-b135-153eb6ac3118

Full Article: https://www.nhs.uk/conditions/social-care-and-support-guide/practical-tips-if-you-care-for-someone/how-to-care-for-someone-with-communication-difficulties/

Easy Read

Some people can benefit from written information being into an easy-read format. This involves the use of simple sentences and language and the use of photos or pictures to support the meaning of the written words. When producing written information for patients, it may be worth considering accessibility for patients who may be non-verbal or have a learning disability. An easy –to –read, information resource with picture and images and dew words can support people with learning disabilities to have a greater understanding of information and support their decision making.

Full Article: https://abilitynet.org.uk/factsheets/what-easy-read

Talking Mats

Talking Mats is 'a visual framework that uses picture symbols to help people with a communication difficulty communicates more effectively'. Using pictures to represent topics and options and a visual scale with people with little or no speech and people who have difficulty in understanding speech can assist them to express their wishes about what will occur in their own life. Service providers, including case managers, can use this tool to help the person with disability consider and discuss a variety of options. The pictures are placed on a mat so that the person with disability can look at the options and choices available and then move them using the visual scale to indicate how they feel about each option. The visual scale might include symbols for liking something, for being unsure and for definitely not liking or wanting something. More complex visual scales can be created, depending on the person's needs and abilities.

Many people with a variety of disabilities use Talking Mats successfully. Nevertheless, there are some people for whom this system is not suitable. Murphy and Cameron (2005) suggested that to use Talking Mats successfully, the person using the mat must be able to recognise picture symbols and must be able to understand at least two keywords at a time. The person must also have a reliable way of confirming his or her views so that the case manager or service provider can be sure that the placement of pictures on the mat does in fact reflect the person's views.

Talking Mats are now classified as an evidence based communication tool, with both physical and digital versions. However, they should always be used alongside other methods of communication, not instead of them.

Full Article: https://www.talkingmats.com/about/what-is-a-talking-mat/

Objects of reference

Objects of reference could be items such as pictures, toys, clothes and food. They may have a special meaning to someone. They could be used to reinforce a message you are trying to communicate, or to set the environment before communicating, for example a particular toy or photo may be comforting to an individual and could be used as an opening when beginning a conversation.

Braille

Braille is a system of raised dots that can be read with the fingers by people who are blind or who have low vision.

Learning braille from a young age has important benefits for children with vision impairment. It can help with literacy, as braille is a much better way to understand punctuation, grammar and spelling than audio.

To just pick up a book and be able to read it is a lovely thing in life that everybody should experience. Without braille that's never going to be accessible to her.

Full Article: https://www.rnib.org.uk/living-with-sight-loss/education-and-learning/braille-tactile-codes/why-is-braille-important/

Images and pictures

Images and pictures can be used to help people learn, attract their attention and explain things. We process images at a much faster rate than words and they are often easier to understand.

You could use images and pictures in a wide range of social care settings.

- Images and pictures are a great way of socially interacting with someone you are supporting.
- There are widely recognised health and safety images that can warn people of potential risks.

Communication aids

Communication aids are designed to support people who have difficulties with speaking or understanding what is being said to them.

This includes everything from bespoke technological devices, to picture books.

Communication aids are often used by people with learning disabilities, autism and other disabilities who struggle to communicate by speaking.

You might hear communication aids referred to as AAC devices. AAC stands for augmentative and alternative communication.

Full Article: https://www.sense.org.uk/information-and-advice/technology-mobility-aids-and-devices/communication-aids/

Checking people with Learning Disabilities understanding by mirroring their terminology

Mirroring terminology is a valuable approach when communicating with individuals who have **learning disabilities**. By using language and expressions that align with their understanding, we can create a more inclusive and supportive environment. Mirroring can be used to show that someone is listening to you, rather than just hearing you.

For more information https://www.wellandgood.com/mirroring-communication-technique/

Checking people with Learning Disabilities understanding by mirroring their terminology

In psychology, the term mirroring refers to when we unconsciously imitate someone else's behaviour in social interactions. This can include body language, facial expressions, and tone of voice (Chartrand & Bargh, 1999). Researchers believe mirroring is an automatic and involuntary process.

Mirroring communication technique is a practice that can create closeness, mirroring means matching an individual's verbal and non-verbal cues during an interaction. Typically, it involves reflecting someone's words, tone of voice, body language, or positions, "If you've ever seen two people in conversation sitting in the same position, crossing or uncrossing their arms or legs at the same time, leaning in toward each other, or even speaking in the same tone of voice, you've witnessed mirroring.

Further, mirroring can be used to show that someone is listening to you, rather than just hearing you.

For more information https://www.wellandgood.com/mirroring-communication-technique/

Communicating with people with a learning disability

When communicating with individuals who have **learning disabilities**, it's essential to use language that resonates with their understanding.

Here are some examples of **mirroring terminology**:

1. Instead of saying "intellectual disability," you can use "learning difference" or "thinking differently."
2. Rather than "challenging behaviour," consider saying "difficult moments" or "expressing feelings."
3. Instead of "autism," you might say "autism spectrum" or "neurodiversity."
4. Use "accessible" instead of "easy to understand" or "user-friendly."
5. Replace "non-verbal" with "using other ways to communicate."

Remember, the goal is to create an inclusive and supportive environment by meeting people where they are

To delve deeper into effective communication with individuals who have learning disabilities, consider exploring the following resources:

1. **Mencap**: They provide a comprehensive guide on **communicating with people with learning disabilities**. Some key tips include:
    - **Speak directly to the person** unless advised otherwise.
    - Keep communication **short and in plain English**.

  - Inquire if they have a **communication passport** or **hospital passport** that offers advice on how best to communicate with them[1].
  - Visit the Mencap webpage for more information.

2. **Royal College of Nursing (RCN)**: Their clinical guidance emphasizes:
  - **Direct communication** with the individual.
  - Using **plain English** and keeping messages concise.
  - Checking if they have a **communication passport** or **hospital passport**[2].

Remember that everyone is unique, so take the time to ask the person you're communicating with what works best for them.

Full Article: https://www.mencap.org.uk/learning-disability-explained/communicating-people-learning-disability

Communicating with people with a learning disability

Challenge your idea of what communication is, understand and make yourself understood.

Making communication work

Communication isn't just about talking, it's also listening.

When you're communicating with someone with a *learning disability*, think about your tone of voice and your body language, as well as the words you use.

Being a good communicator

To be a good communicator with people with a learning disability you need to:

- use *accessible* language
- avoid jargon or long words that might be hard to understand.
- be prepared to use different communication tools
- follow the lead of the person you're communicating with
- go at the pace of the person you're communicating with, check you have understood and be creative.

Makaton

Makaton is a language programme that uses signs, symbols and speech; giving a person different options when communicating.

We've worked with The Makaton Charity on some useful information about Makaton and how it is used.

"Sometimes I've got the words in my mind, and I'm trying to explain it in the best possible way, but it doesn't always come out."

Top tips for communication

Remember, everybody is unique, so take the time to ask the person you're communicating with what works best for them.

In person: Many people with a learning disability prefer face to face and one to one communication.

In writing: Use bigger text and bullet points, and to keep writing at a minimum. Too much colour can make reading harder for someone as well.

On the phone: Speak slowly and clearly, using easy to understand words.

You may also find these tips useful:

- Find a good place to communicate in - somewhere without distraction. If you are talking to a large group be aware that some people may find this difficult.
- Ask open questions; questions that don't have a simple yes or no answer.
- Check with the person that you understand what they are saying e.g. "the TV isn't working? Is that right?"
- If the person wants to take you to show you something, go with them.
- Watch the person; they may tell you things by their body language and facial expressions.
- Learn from experience - you will need to be more observant and don't feel awkward about asking parents or carers for their help.
- Try drawing - even if your drawing isn't great, it might still be helpful.
- Take you time, don't rush communication.
- Use gestures and facial expressions. If you're asking if someone is happy or unhappy, make your facial expression unhappy to reinforce what you're saying.
- Be aware that some people find it easier to use real objects to communicate, but photos and pictures can really help too.

Remember, all communication is meaningful, but you may need to work harder to understand.

Further help

Many people with a learning disability can use or recognise some signs. Signalong and Makaton are both Sign Supported English systems. They are based on British Sign Language (BSL), but are used to support the spoken word.

- Visit the Signalong website or the Makaton website to find out more.
- Visit the British Deaf Association website to find out more about BSL.
- Talking Mats are a communication system that uses symbols and other images.
- Widgit produce software symbols to help with communication and accessibility.
- Symbol World is a *website* run by Widget for symbol users that includes nursery rhymes, stories and a monthly magazine.

Full Article: Communicating with people with a learning disability#:~:text=To%20be%20a%20good%20communicator%20with%20people%20with,with%2C%20check%20you%20have%20understood%20and%20be%20creative.

Full Article: https://www.mencap.org.uk/sites/default/files/2016-12/Communicating%20with%20people_updated%20%281%29.pdf

‘Professional’ language **Bryony Shannon Social care 28th October 2023**

“Practitioners use language as a way of creating distance. Occasionally this may arise from lack of confidence and institutional expectations. These causes of “othering” merit attention.” **John Sell** [1]

When I posted a link to my previous blog post on Twitter, John Sell responded with the comment above.

I’ve written a lot about why language matters. About what the words and phrases we use reveal and perpetuate about our attitudes and behaviours, and how changing this language can help shift our practice to be more relational, rights-based, and human. But maybe I haven’t really delved far enough into the reasons *why* we continue to use this vocabulary.

Why we still think it’s ok.

So, here are ten reasons I believe lie behind our use of dehumanising, stigmatising, and ‘othering’ language.

They are reasons – not excuses.

There is no excuse.

1. It’s everywhere

Dehumanising, stigmatising, and othering language is everywhere in social work and social care.

It forms the content of our job descriptions and job adverts (‘you will be required to work with complex cases’, ‘you will be working with vulnerable service users’) and the structure of our departments (‘Complex needs team’, ‘Challenging behaviour unit’).

It’s written into local and national policies, procedures, and practice guidance (‘Death of a service user policy’. ‘Working with uncooperative and hard to engage families’).

It’s built into our ‘case management systems’ – including in that term itself.

It’s embedded in the national data collections and statutory reporting requirements (‘Client level data’. ‘Cohorts of service users’. ‘Care settings’.)

It features in media coverage of social care (‘Care for UK’s most vulnerable faces ‘collapse’’) and in government press releases (‘NHS to expand services to keep vulnerable out of hospital’).

The ubiquity of this language offers some legitimacy to its use.

When something is so prolific, so ingrained, we easily accept it without challenge.

Without thought.

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[1] johntsell on X: "@BryonyShannon Practitioners use language as a way of creating distance. Occasionally this may arise from lack of confidence and institutional expectations. These causes of "othering" merit attention." / X

2. We learn it

Social work degrees are advertised as ‘allowing you to make a positive difference in vulnerable and disadvantaged people’s lives’ and ‘helping you build the knowledge and skills to help shape the lives of vulnerable people’. ‘You’ll learn how to work with vulnerable adults’ and ‘gain first-hand experience from service users’.

University departments ‘work closely with service users when recruiting students’ and ‘collaborate with a wide range of service users’ to develop course content.

Entry requirements include relevant social care experience, which could include experience in a ‘care setting’ or ‘personal experience as a service-user’.

You’ll prepare for the ‘challenging role of a social worker’ through simulations including ‘engaging a service user’, ‘assessed role play interviews with a service user’ and have the ‘opportunity to interact with service users and their carers’.

Placements include ‘working with people with complex needs’.

We teach this language.

We are taught these words.

3. We like it

This ‘professional’ language offers us an identity. Using these words demonstrates we’re in the gang. We’re true, genuine members of the profession.

We belong.

Affirming and validating, albeit at the expense of ‘others’, who definitely don’t belong.

These words also offer us and our teams and organisations credibility.

Give purpose to our roles.

‘Protecting our most vulnerable’. ‘Caring for the elderly’. ‘Supporting the disabled’. ‘Looking after those with learning disabilities’. ‘Safeguarding vulnerable groups’. ‘Keeping those with dementia safe and sound’. ‘Helping the frail out of hospital’. ‘Maintaining the disabled, elderly and those otherwise in need of care within the community.’

Protecting. Looking after. Caring for. Safeguarding.

Assisting weak, helpless ‘others’.

That’s our job, isn’t it?

And using this language demonstrates our expertise. Shows that we have all the knowledge and all the answers.

But this notion that we’re the experts doesn’t sit at all well in a relational approach, where lived experience should be valued just as highly as learned experience. Where people are recognised as the experts in their own lives. Where listening and curiosity and being alongside and learning together is key. Where it’s often much better to say, ‘I don’t know – let’s find out together’ than ‘I know, I’ll tell you what you need to do’.

4. It’s efficient

Our social care sorting offices prioritise efficiency over empathy. We measure how many how much how long. We work in ‘fast-paced’, ‘busy’ teams. We have targets for the number of ‘assessments’ or ‘reviews’ completed in a week. Support is ‘commissioned’ and ‘delivered’ with just enough time for ‘tasks’, not conversations and compassion.

And when we have deadlines and targets to meet, it’s quicker to make assumptions and to categorise than it is to ask how are you? What would you like to talk about today? What’s important to you right now?

It’s quicker to use acronyms and labels and reliable stock phrases in our assessments and our reviews.

Labelling people means we can process them more quickly through our system, and slot them more easily into our standard service solutions.

“The majority will be your four calls a day stuff.”

It’s also quicker to say ‘my cases’ than ‘the people I’m working with’. ‘The LD team’ than ‘the Learning Disabilities Team’. ‘Customers’ rather than ‘the people we serve’. ‘Our service users’ rather than ‘the people we support’. ‘Chair 7’ rather than ‘the person sitting in chair 7’. ‘Mum’ rather than asking and remembering people’s names.

And anyway, you know who I mean when I refer to ‘the vulnerable’ don’t you?

You know.

Them.

Those.

Not us.

5. It’s effective

Often, we apply labels like ‘vulnerable’ and ‘complex’ and ‘high risk’ to people to make sure they gain entry to our system. To demonstrate eligibility for services and support. These labels help us to screen and ‘RAG rate’ and prioritise and triage. They help us justify decisions and costs to panels. Their inclusion in reports and funding bids helps us evidence ‘demand’, ‘need’ and the ‘worthiness’ of our proposals.

Without these labels, no one passes go.

While some terms open doors to services and support, we use those same terms – and others – to quickly slam doors shut. We label people as ‘too vulnerable’, ‘too complex’, ‘too high risk’ as a way of saying ‘go away, you can’t come in’.

To shift responsibility elsewhere.

Phew.

This language helps to give us a sense of control. It ensures we can frame people’s experiences and behaviour and identity through our own lens. Helps us assert our power and authority over ‘users’, kept submissive by our approach.

Sometimes we feel powerless within ‘the system’.

Feel we’re drowning.

These familiar words help anchor us.

Keep us safe.

6. It justifies our actions

This language is deployed to legitimise. During the COVID-19 pandemic, decisions were made to ‘protect our most vulnerable’. And more recently, councils declaring or facing bankruptcy have noted that all new spending will cease, except for ‘protecting vulnerable people’ / ‘looking after vulnerable residents’ / ‘safeguarding the most vulnerable’ – validating actions while simultaneously blaming precarious budget situations on ‘the increased complexity of vulnerable adults, children and families needing support’, ‘an ageing population’, ‘elderly care’ and ‘growing demand for core services like social care for vulnerable children and adults’.

Dehumanising people helps reduce empathy. Seeing ‘cases’ rather than people makes it easier to do to and for, not with. To assess and to judge and to place and to exclude.

This language helps us to defend our practice and our systems and our institutions.

To justify our prejudices and priorities.

The blaming labels we apply to people (‘difficult’, ‘hard to reach’, ‘refusing to engage’…) allow us to place the ‘problem’ firmly with them.

Nothing to do with us.

And classifying people’s behaviour as ‘challenging’ or ‘aggressive’ makes it easier to gloss over the causes, and to rationalise restrictions and restraint.

Our dehumanising language helps us justify actions that are inhumane.

But in removing the humanity from other people, we diminish our own humanity.

And excusing current practice by deflecting and defending means there’s never any challenge.

Never any change.

7. It helps us cope

Distancing people from us by applying labels that remove their humanity can make it easier to cope. In the same way that we turn off the news when everything just feels overwhelmingly awful and hopeless, ensuring this element of separation is our survival mechanism. It shields us from the pain and trauma of people’s lives. It protects us from acknowledging that their reality could just as easily be ours too.

‘The elderly.’ ‘Those who are vulnerable’. Them. Not us.

This detachment also means we don’t have to show our own emotions or be vulnerable ourselves.

8. We’re not challenged

Maybe we’re not aware of the impact or the implications of our words, or maybe we’re using them with deliberate intent or disregard. Either way, our continued use of these labels and this jargon suggests we’re spending time with people who aren’t challenging our language. Maybe we’re comfortably surrounding ourselves with people who are using it too. Maybe the people we’re communicating with are too daunted to question or object. Maybe we're just not working closely with and alongside people with cause to draw on care and support and their allies and advocates, who would call out this vocabulary in an instant if they were granted a seat at our table.

9. We don't challenge

It's not easy to admit that we don't understand the language people around us are using. Especially when we feel that everyone else 'gets' the jargon and acronyms that remain alien and meaningless to us. And it can be hard to question the language someone else is using, even if we feel it's damaging.

So sometimes it's less scary to stay quiet and not ask what certain words mean, or why certain phrases are used so casually and so callously.

Sometimes it's easier just to use them too.

10. Prejudice

Though we'll undoubtedly be reluctant to admit it, or even appalled at the thought, much of this language results from, and exposes, prejudice and ableist beliefs.

Our automatic labelling of older and disabled people as 'vulnerable', who need 'looking after', 'protecting', 'caring for'.

Describing where people live as 'settings', 'facilities', 'units'. Institutions to 'place' people in. Not 'home' – not like us.

Referring to the things people do as 'activities'. 'Accessing the community' – but not part of a community.

Defining the way people behave as 'risky'. 'Challenging'. 'Non-compliant'. Not human.

I've heard and read claims like 'I don't like the term 'service user' / 'case' / 'vulnerable'… but I don't know what to use instead' so many times. As I demonstrated in my blog post about labels, the search for the perfect 'label' and the 'what do we call 'them'?' debate has spanned both decades and continents.[2]

The fact that we can't possibly consider substituting the word 'person' for service user / client / customer / patient / case, or use 'us' instead of 'them', speaks volumes about how distant and detached we've become.

Desensitised.

Dehumanised.

Flipping the narrative

"Systems built for humans are not necessarily humane systems. They can be disempowering and humiliating. They can overlook lives instead of witnessing them… While hope and healing lie in relationships, too often our human systems are cool, distant and transactional. Murmurs of apology can be heard everywhere, admissions that these are just the rules and roles and hopefully others can appreciate that. Systems like that are hard on those who seek help, and hard on those who deliver it."

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[2] https://rewritingsocialcare.blog/2019/12/20/labels/

Gord Tulloch and Sarah Schulman [3]

Principles of social justice, human rights, collective responsibility, and respect for diversities are central to social work.[4] And yet so much of our language is oppressive, designed to exclude rather than include. Eroding rather than upholding people's rights and identity.

In a session facilitated by Tricia Nicoll at the recent #SocialCareFuture gathering in Manchester, there was a conversation about flipping the idea of 'professional language', so it becomes 'professional' to use kind, respectful and plain language, and unprofessional to use, or not to challenge, words that dehumanise and other and blame.

One of Tricia's four tests for gloriously ordinary lives is a test about language. She asks us to ask ourselves whether we would use this language in our kitchen with our family, or at the café or pub with our mates. [5]

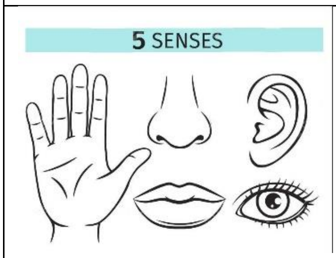
If the words we use with and about the people we support and serve aren't words we'd use with and about the people we love, they're probably words that get in the way of gloriously ordinary lives.

There's always a more human, humane word.

There's always a more human, humane world.

Full Article: https://rewritingsocialcare.blog/2023/10/28/professional-language/

Sensory Overload: What It Is and Why It Happens



Sensory overload occurs when you're faced with more sensory input than your brain can process. If you've ever turned off the car radio so you could focus on what you see through your windshield, you've regulated sensory input.

It may not make sense at first — after all, how can music affect the way your eyes work? — but your brain must process all the input it receives. Eliminating the music you hear makes it easier to react to what you see outside the car.

So, what happens when a person is bombarded with multiple types of sensory input that they can't regulate?

Some examples of situations that can trigger sensory overload include:

- Loud noises or music
- Crowded spaces
- Emotionally intense people or groups
- Drastic environmental changes (temperature, light, etc.)
- Unexpected or unwanted physical contact (hugs, etc.)

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[3] The trampoline effect: redesigning our social safety nets, Gord Tulloch and Sarah Schulman, Reach Press, 2020

[4] https://www.ifsw.org/what-is-social-work/global-definition-of-social-work/

[5] https://www.gloriouslyordinarylives.co.uk/the-five-tests

- Heavy traffic
- Tactile triggers (scratchy or uncomfortable clothing, etc.)
- Intense smells

What causes sensory overload?

The input from your environment doesn't stop at your senses. Several areas of the brain process the sensations you experience. When this processing can't keep up with new input, the result is sensory overload.

The reasons for this mismatch between input and sensory integration can vary. A busy environment might be the culprit. For example:

- The person experiencing the overload might be tired or hungry, so their brain circuitry might not work as well as usual.
- Some people's neurology might be sensitive because of mental health conditions or medical issues.

Sensory overload activates a fight, flight, or freeze response in which you try to escape triggers. This is when you see signs like meltdowns in children and irritability in adults.

It's more than just an aversion to loud noises. Sensory overload can affect any one of your senses, such as:

- hearing
- sight
- smell
- taste
- touch
- balance
- body position awareness

Sometimes, more than one sense is overwhelmed. For example, a student at a school assembly could feel overwhelmed by the sounds echoing in the gym, the glare of the fluorescent lights, and the movement and presence of all the students around them.

Which conditions are linked to sensory overload?

Even though sensory overload can happen to any person at any age, there are many health and developmental conditions where it's more likely to occur.

ADHD

Sensory overload is a characteristic of attention deficit hyperactivity disorder (ADHD). Not all people with ADHD experience sensory overload and overstimulation, but the chances increase given certain ADHD factors, such as:

- self-regulation difficulties
- lack of awareness to surroundings
- hyperfocus
- hyperactivity

- impulsivity
- inattentiveness
- atypical response to stimuli

Anxiety

The connection between anxiety and sensory overload goes both ways. People experiencing anxiety have a higher chance of experiencing sensory overload, which in turn can cause anxiety.

Autism

It's estimated that about 90% of autistic people have sensory experiences that are atypical, according to a 2020 review. This means that they can be more responsive or less responsive to sensory input than allistic (nonautistic) people.

Different neurotypes have different sensory overload thresholds, and an autistic person might be overwhelmed in situations that don't affect allistic people.

Concussion and post-concussion syndrome

A concussion is a mild traumatic brain injury (TBI). It may be followed by post-concussion syndrome, which describes symptoms that linger longer than expected.

Light and sound sensitivity is a common sign of TBI and can affect quality of life. A 2019 studyTrusted Source revealed a connection between TBI and post-traumatic stress disorder (PTSD) in military personnel because of altered sensory processing.

Fibromyalgia

Fibromyalgia is a pain-causing condition affecting the entire body.

A 2021 study reports that people with fibromyalgia have higher sensitivity not just to pain, but to other sensations too, including light, smell, and sound.

And a 2014 brain imaging studyTrusted Source on 35 women with fibromyalgia and 25 women without showed that this hypersensitivity is reflected in different patterns of brain activity between people with and without fibromyalgia. The authors also note that this sensory sensitivity was linked with spontaneous pain.

Multiple sclerosis

Multiple sclerosis (MS) is an autoimmune condition that affects nerve cells. Sensory overload is a common symptom of MS, and triggers include:

- too many voices at the same time
- loud and busy environments, such as stores and restaurants
- fatigue
- unfamiliar spaces
- crowds

PTSD

People with PTSD often experience sensory overload triggered by hypervigilance. This is a state of continuous anxiety as a defence mechanism against perceived threat. Hypervigilance demands a high amount of sensory input, which can result in overload.

What does sensory overload feel like?

Sensory overload can make a person more sensitive than usual to input from their environment.

For example:

- Sudden sounds may take your breath away and make you flinch.
- You need to turn down the lights because your head is starting to ache.
- Textured fabric burn your skin, and clothing tags itch unbearably.

Sensory overload symptoms may be cognitive. If you can't focus unless it's pin-drop quiet, or if speaking over the TV volume takes too much energy, your senses may be overwhelmed.

Emotional changes can result from sensory overload. These include:

- irritability
- anxiety
- restlessness
- crying
- agitation
- anger

Children may experience similar reactions but express them in different ways. A child may have a full meltdown instead of simply being irritable.

If your child is overwhelmed by something, the trigger may not be easy to decipher. While your child may put their hands over their ears because of sound sensitivity, a body awareness issue might be harder to identify.

How do you calm down sensory overload?

There aren't any medications you can use to offset sensory overload, but there are strategies and lifestyle modifications that can help. It's also beneficial to treat any conditions that occur with sensory overload.

Identify the behaviour

The first step in dealing with sensory overload is to assess reactions in context. This will help you know if the reaction is related to sensory overload. It's useful to keep a log so you can identify patterns.

For example, you may notice your child is very emotional at the end of band or PE days at school. Loud, clumsily played instruments can be overpowering. Quickly moving bodies paired with squeaking runners, thudding feet, and echoing shouts in a gym, all under fluorescent lights, can be too much.

Plan for recovery

On those band and PE days, it can help to keep your child's schedule clear of extracurricular activities or visits with friends. This could help them quietly recover.

Similarly, if you're irritable after working next to construction all day, it's OK to forgo evening plans.

Anticipate and avoid

While your child might not be allowed to miss PE at school, the same mandatory attendance doesn’t apply to extracurricular activities.

For example, if the hustle, glaring lights, and echoes at the skating rink are causing an issue, you can weigh this against the benefits of skating lessons and consider choosing another activity.

Reduce the impact

If you can’t avoid a sensory-triggering environment, you can reduce its impact.

You can try using protective items, such as sunglasses, earplugs, or noise-cancelling headphones. Cutting out shirt tags can help, as well as choosing the right fabric for clothing.

Practice self-calming

People of all ages can learn self-calming techniques that can help them get through episodes of sensory overload. Some strategies include:

- yoga
- meditation and mindfulness training
- breathing exercises
- counting to 10
- an exit strategy to change your environment
- a calming activity, such as reading a book
- sensory fidgets like a squeeze ball

Healthcare

Sensory overload may be easier to manage when your health is good. A balanced diet, adequate hydration, and restful sleep all contribute to your brain’s health. This way, your brain can cope better with sensory integration challenges.

Takeaway

Understanding sensory overload makes it easier to manage it. If you’re experiencing too much sensory input, remember that taking a break from your current activity can ease your stress and discomfort.

If you’re dealing with a person who’s acting out, the cause may be sensory overload. Assessing the environment can give you clues to how you can help. For example, you can reduce noise and light levels, or simply give them space.

It’s also helpful to remember that sensory overload is not a choice a person makes. It’s no one’s fault, and people who experience it can benefit from empathy and support.

Full Article: https://psychcentral.com/health/sensory-overload

Intellectual disability and communication

People with intellectual disability communicate in different ways. Some people use their voice to speak, but others may use hand signals, pictures or other tools to help them communicate without speaking.

People with intellectual disability communicate in different ways. Some people use their voice to speak, but others may use hand signals, pictures or other tools to help them communicate without speaking. This is called augmentative and alternative communication (AAC).

Many people with intellectual disability use a mix of different communication methods, which is called multimodal communication.

The most important thing when talking with someone with intellectual disability is to understand and respect their unique way of communicating.

Intellectual disability can affect communication in different ways for different people. Some people might have a hard time communicating beyond their basic needs.

Here are some examples of communication difficulties that you might face if you have intellectual disability:

- Reading – this means being able to understand words and sentences when you read them.
- Writing – this is being able to put your thoughts and ideas into written words, while also using correct spelling and grammar.
- Speaking – this is using your voice to talk and being able to say words clearly, even if they are long or hard to say.
- Understanding – this is being able to learn and understand new things, as well as following instructions.
- Expression – this is being able to tell others what you want or need, as well as sharing your thoughts and ideas.
- Social communication – this means being able to talk to others in a way that makes sense, like taking turns in conversation and knowing what to say in different situations.
- Engagement – this means some people might communicate in ways that are different from what we are used to, and some might not seem to be communicating at all.

Some people with intellectual disability have trouble communicating with words. They may use other actions or behaviours to show how they feel. But sometimes, these behaviours can be dangerous and cause harm to themselves or others.

It’s important to find new ways for them to communicate without hurting anyone. A speech therapist can help them find safer ways to express themselves.

How communication difficulties affect your life

When you have trouble communicating, it can mean you’re not able to do things by yourself. It might be hard to:

- make choices
- ask for help
- express your opinions
- tell stories about yourself and others
- talk about a health problem
- find out about things.
- Some people with intellectual disability might need extra help to develop relationships, work and live independently.

Relationships

If you have trouble communicating, it can make it hard to socialise and spend time with other people.

Children with intellectual disability have fewer friends than other children.

For adults, intellectual disability can lead to loneliness and isolation.

Employment

Some people with intellectual disability might have trouble talking to teachers, bosses or people they don’t know.

This can make it hard to study or get a job.

Many employers don’t know how to support people with communication difficulties at work.

Living independently

Some people with intellectual disability might have trouble living by themselves.

They might not be able to make their own choices.

They might have trouble talking to others about what they need.

Strategies to help communication

Each person with intellectual disability communicates in specific ways.

The best way to communicate with them is to understand the methods they use to get their message across, and work with them using their unique system.

This might involve using a communication book, an about me page, a communication passport, or a small card with tips for communication partners.

In general, you should:

- give the person plenty of time to form their message and to understand what you’re saying
- ask them to repeat themselves if you don’t understand them
- ask them politely to use a different way to get their message across (for example, drawing or showing you something)
- use visuals and gestures
- make sure they have understood you
- talk to them often so you get used to communicating with each other.

People with intellectual disability might have trouble paying attention or concentrating on communication.

You should consider how the environment might affect the person's ability to communicate. Minimise distractions if you can. Noisy and unfamiliar places can also make it hard to communicate.

Full Article:
https://www.communicationhub.com.au/CommunicationHub/Communication_Hub/Resources/Fact_Sheets/Intellectual_disability.aspx

Sensory differences - a guide for all audiences

Processing everyday sensory information can be difficult for autistic people. Any of their senses may be over- or under-sensitive, or both, at different times. These sensory differences can affect how they feel and act, and can have a profound effect on a person's life. Here we help you to understand autism, the person and how to help.

You can also find out about synaesthesia, therapies and equipment.

Too much information

Sometimes an autistic person may behave in a way that you wouldn't immediately link to sensory differences. A person who finds it difficult to process everyday sensory information can experience sensory overload, or information overload. Too much information can cause stress, anxiety, and possibly physical pain. This can result in withdrawal, distressed behaviour or meltdowns.

"If I get sensory overload then I just shut down; you get what's known as fragmentation...it's weird, like being tuned into 40 TV channels." - an autistic person

If someone is having a meltdown, or not responding, don't judge them. There are things that you can do to help. This can make a world of difference to autistic people and their families. Often, small changes to the environment can make a difference. Creating a sensory profile may help you to work out what changes are needed. Three points to remember are:

1. be aware. Look at the environment to see if it is creating difficulties. Can you change anything?
2. be creative. Think of some positive sensory experiences
3. be prepared. Tell the person about possible sensory stimuli they may experience in different environments.

Sensory differences

Here we look at some of the effects of hypersensitivity or hyposensitivity to sights, sounds, smells, tastes, touch, balance and body awareness, and ways you could help.

Sight

Under-Sensitive

- objects appear quite dark, or lose some of their features
- central vision is blurred but peripheral vision quite sharp

- a central object is magnified but things on the periphery are blurred
- poor depth perception, difficulties with throwing and catching, clumsiness.

Over-Sensitive

- distorted vision - objects and bright lights can appear to jump around
- images may fragment
- easier and more pleasurable to focus on a detail rather than the whole object
- has difficulty getting to sleep as sensitive to the light.

You could make changes to the environment, such reducing fluorescent lighting, providing sunglasses, using blackout curtains and/or creating a workstation in the classroom - a space or desk with high walls or divides on both sides to block out visual distractions.

Sound

Under-Sensitive

- may only hear sounds in one ear, the other ear having only partial hearing or none at all
- may not acknowledge particular sounds
- might enjoy crowded, noisy places or bang doors and objects.

You could help by using visual supports to back up verbal information, and ensuring that other people are aware of the under-sensitivity so that they can communicate effectively. To meet the person’s individual sensory need, include experiences they enjoy in their daily timetable.

Over-Sensitive

- noise can be magnified and sounds become distorted and muddled
- may be able to hear conversations in the distance
- inability to cut out sounds – notably background noise - leading to difficulties concentrating.

"Do you hear noise in your head? It pounds and screeches. Like a train rumbling through your ears."

- Powell, J., in Gillingham, G. (1995), page 41

You could help by:

- shutting doors and windows to reduce external sounds
- preparing the person before going to noisy or crowded places
- providing ear plugs and music to listen to
- creating a screened workstation in the classroom or office, positioning the person away from doors and windows.

Smell

Under-Sensitive

- some people have no sense of smell and fail to notice extreme odours (this can include their own body odour).
- some people may lick things to get a better sense of what they are.

You could help by creating a routine around regular washing and using strong-smelling products to distract people from inappropriate strong-smelling stimuli (like faeces).

Over-Sensitive

- smells can be intense and overpowering. This can cause toileting problems
- dislikes people with distinctive perfumes, shampoos, etc.

"Smells like dogs, cats, deodorant and aftershave lotion are so strong to me I can't stand it, and perfume drives me nuts."

- Gillingham, G. (1995), page 60

You could help by using unscented detergents or shampoos, avoiding wearing perfume, and making the environment as fragrance-free as possible.

Taste

Under-Sensitive

- likes very spicy foods
- eats or mouths non-edible items such as stones, dirt, soil, grass, metal, faeces. This is known as pica.

Over-Sensitive

- finds some flavours and foods too strong and overpowering because of very sensitive taste buds. Has a restricted diet
- certain textures cause discomfort - may only eat smooth foods like mashed potatoes or ice-cream.

Some autistic people may limit themselves to bland foods or crave very strong-tasting food. As long as someone has some dietary variety, this isn't necessarily a problem. Find out more about over-eating and restricted diets.

Touch

Under-Sensitive

- holds others tightly - needs to do so before there is a sensation of having applied any pressure
- has a high pain threshold
- may be unable to feel food in the mouth
- may self-harm
- enjoys heavy objects (e.g. weighted blankets) on top of them
- smears faeces as enjoys the texture
- chews on everything, including clothing and inedible objects.
- You could help by:
- for smearing, offering alternatives to handle with similar textures, such as jelly, or cornflour and water
- for chewing, offering latex-free tubes, straws or hard sweets (chill in the fridge).

Over-Sensitive

- touch can be painful and uncomfortable - people may not like to be touched and this can affect their relationships with others
- dislikes having anything on hands or feet

- difficulties brushing and washing hair because head is sensitive
- may find many food textures uncomfortable
- only tolerates certain types of clothing or textures.

"Every time I am touched it hurts; it feels like fire running through my body."

- Gillingham, G. (1995), page 3

You could help by:

- warning the person if you are about to touch them - always approach them from the front
- remembering that a hug may be painful rather than comforting
- changing the texture of food (e.g. purée it)
- slowly introducing different textures around the person's mouth, such as a flannel, a toothbrush and some different foods
- gradually introducing different textures to touch, e.g. have a box of materials available
- allowing a person to complete activities themselves (e.g. hair brushing and washing) so that they can do what is comfortable for them
- turning clothes inside out so there is no seam, removing any tags or labels
- allowing the person to wear clothes they're comfortable in.

Balance (vestibular)

Under-Sensitive

- a need to rock, swing or spin to get some sensory input.

You could encourage activities that help to develop the vestibular system. This could include using rocking horses, swings, roundabouts, seesaws, catching a ball or practising walking smoothly up steps or curbs.

Over-Sensitive

- difficulties with activities like sport, where we need to control our movements
- difficulties stopping quickly or during an activity
- car sickness
- difficulties with activities where the head is not upright or feet are off the ground.

You could help by breaking down activities into small, more easily manageable steps and using visual cues such as a finish line.

Body awareness (proprioception)

Our body awareness system tells us where our bodies are in space, and how different body parts are moving.

Under-Sensitive

- stands too close to others, because they cannot measure their proximity to other people and judge personal space
- finds it hard to navigate rooms and avoid obstructions
- may bump into people.
- You could help by:
- positioning furniture around the edge of a room to make navigation easier
- using weighted blankets to provide deep pressure

- putting coloured tape on the floor to indicate boundaries
- using the 'arm's-length rule' to judge personal space - this means standing an arm's length away from other people.

Over-Sensitive

- difficulties with fine motor skills, e.g. manipulating small objects like buttons or shoe laces
- moves whole body to look at something.

You could help by offering 'fine motor' activities like lacing boards.

Synaesthesia

Synaesthesia is a rare condition experienced by some autistic people. An experience goes in through one sensory system and out through another. So, a person might hear a sound but experience it as a colour. In other words, they will 'hear' the colour blue.

Therapies and equipment

We can’t make recommendations as to the effectiveness of individual therapies and interventions or equipment.

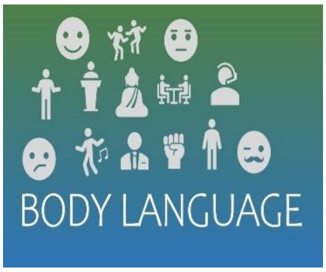
- **Music therapists** use instruments and sounds to develop people's sensory systems, usually their auditory (hearing) systems.
- **Occupational therapists** design programmes and often make changes to the environment so that people with sensory differences can live as independently as possible.
- **Speech and language therapists** often use sensory stimuli to encourage and support the development of language and interaction.
- **Some people say they find coloured filters helpful**, although there is only very limited research evidence. Find out more from https://irlenuk.com/.
- **Sensory integrative therapy** and Sensory Integration Network.
- The https://braininhand.co.uk/ digital self-management support system.

References

Gillingham G. (1995) Autism: handle with care!: understanding and managing behaviour of children and adults with autism. Future Education Inc.

Full Article: https://www.autism.org.uk/advice-and-guidance/topics/sensory-differences/sensory-differences/all-audiences

How Is Body Language Used in Healthcare and Social Care



Body language is a powerful communication tool. It can be used to help the patient feel more at ease, build rapport and create a therapeutic environment. Body language is also important as it helps to identify possible physical or emotional stressors that could lead to injury or illness.

Body Language plays an important role in health and social care settings. It involves non-verbal communication through gestures, facial expressions, and posture.

Effective use of body Language can enhance patient interactions, build trust, and improve overall care delivery. In this guide, I'll outline the key aspects and techniques to use body language effectively in health and social care.

What is Body Language?

Body Language refers to non-verbal signals Like gestures, facial expressions, posture, and eye contact. These signals can convey emotions and intentions, sometimes even more powerfully than spoken words.

Importance in Health and Social Care

In health and social care settings, body language helps care providers connect with patients. It reassures, comforts, and shows empathy. Good body Language can help in assessing a patient's condition and needs.

Key Elements of Body Language

Facial Expressions

Your face can express a wide range of emotions. Smiling, for instance, can make patients feel welcomed and at ease. Raised eyebrows can show surprise or concern, which can be important during consultations.

Eye Contact

Maintaining eye contact shows attentiveness and interest. It helps in building trust and rapport with patients. However, excessive staring can make patients feel uncomfortable, so moderation is key.

Posture

Standing or sitting up straight shows confidence and readiness. Leaning slightly forward indicates interest and attention.

which can suggest defensiveness or disinterest, helps in creating an open and welcoming environment.

Gestures

Hand movements and gestures should be natural and purposeful. They can help in explaining complex medical terms or procedures. Avoid excessive or distracting gestures.

Techniques for Effective Body Language

Building Trust and Rapport

Smile and Open Body Posture

A genuine smile can break the ice and make patients feel comfortable. Open body posture, such as uncrossed arms and legs, shows that you are approachable and willing to Listen.

Appropriate Touch

A gentle touch on the shoulder or hand can provide reassurance. Always ensure the patient is comfortable with any physical contact, as it can vary with cultural and personal differences.

Active Listening

Nodding

This shows understanding and encourages the patient to continue sharing. It signals that you are following along with what they are saying.

Minimal Verbal Encouragement

Using small verbal cues Like "I see" or "Go on" combined with nodding can show you're engaged in the conversation.

Communicating Empathy and Compassion

Mirroring

Mirroring involves subtly mimicking the patient's body language. It can help in building a sense of understanding and connection.

Open Hand Gestures

Using open hand gestures while speaking can make you appear more open and honest. It can also help in making patients feel more at ease.

Assessing Patient Needs

Observing Non-Verbal Cues

Pay attention to patients' body language. Watch for signs of discomfort, such as fidgeting, Lack of eye contact, or crossed arms. These cues can indicate anxiety, pain, or reluctance to share information.

Using Proxemics

Proxemics refers to the personal space between individuals. Respecting patients' personal space can make them feel more secure. Adjust your distance based on the patient's comfort level and the context of the interaction.

Special Considerations

Cultural Sensitivity

Body Language can vary significantly across cultures. For instance, in some cultures, direct eye contact may be considered rude. Be aware of these differences and adapt accordingly.

Working with Children

Children may express themselves differently than adults. Use more exaggerated facial expressions and gestures to communicate effectively. Getting down to their eye Level can help in building rapport.

Interacting with Patients with Disabilities

Some patients may have physical or cognitive disabilities that affect their ability to use or interpret body language. Be patient, and use clear, simple gestures. Always ensure that your body Language aligns with your verbal communication.

Training and Improvement

Regular Training Sessions

Participating in regular training sessions on non-verbal communication can enhance your skills. Role-playing scenarios can provide practical experience.

Feedback and Self-Reflection

Seek feedback from colleagues and patients to improve your body Language. Reflect on your interactions and identify areas for improvement.

Conclusion

Effective body language can significantly enhance the quality of care you provide in health and social care settings. By paying attention to facial expressions, eye contact, posture, and gestures, you can build trust, show empathy, and better understand your patients' needs.

Cultural sensitivity and adapting your approach to different patient groups are also crucial. Regular training and self-reflection can help you

continually improve your non-verbal communication skills. Use these techniques to create a positive and supportive environment for your patients.

By mastering the art of body language, you can make a meaningful difference in the lives of those you care for.

Full Article: https://carelearning.org.uk/blog/communication-blog/how-to-use-body-language-in-health-and-social-care/

Understanding Body Language and Facial Expressions

Understanding Body Language and Facial Expressions

By Kendra Cherry, MSEd

Updated on February 23, 2023

Reviewed by Steven Gans, MD

Body language refers to the nonverbal signals that we use to communicate. These nonverbal signals make up a huge part of daily communication. In fact, body language may account for between 60% to 65% of all communication.[1]

Examples of body language include facial expressions, eye gaze, gestures, posture, and body movements. In many cases, the things we *don't* say can convey volumes of information.

So, why is body language important? Body language can help us understand others and ourselves. It provides us with information about how people may be feeling in a given situation. We can also use body language to express emotions or intentions.[2]

Facial expressions, gestures, and eye gaze are often identified as the three major types of body language, but other aspects such as posture and personal distance can also be used to convey information. Understanding body language is important, but it is also essential to pay attention to other cues such as context. In many cases, you should look at signals as a group rather than focus on a single action.

This article discusses the roles played by body language in communication, as well as body language examples and the meaning behind them—so you know what to look for when you're trying to interpret nonverbal actions.

Facial Expressions

Think for a moment about how much a person is able to convey with just a facial expression. A smile can indicate approval or happiness. A frown can signal disapproval or unhappiness.

In some cases, our facial expressions may reveal our true feelings about a particular situation. While you say that you are feeling fine, the look on your face may tell people otherwise.

Just a few examples of emotions that can be expressed via facial expressions include:

- Happiness
- Sadness
- Anger
- Surprise
- Disgust
- Fear
- Confusion
- Excitement
- Desire
- Contempt

The expression on a person's face can even help determine if we trust or believe what the individual is saying.

There are many interesting findings about body language in psychology research. One study found that the most trustworthy facial expression involved a slight raise of the eyebrows and a slight smile. This expression, the researchers suggested, conveys both friendliness and confidence.[3]

Facial expressions are also among the most universal forms of body language. The expressions used to convey fear, anger, sadness, and happiness are similar throughout the world.

Researcher Paul Ekman has found support for the universality of a variety of facial expressions tied to particular emotions including joy, anger, fear, surprise, and sadness.[4]

Research even suggests that we make judgments about people's intelligence based upon their faces and expressions.

One study found that individuals who had narrower faces and more prominent noses were more likely to be perceived as intelligent. People with smiling, joyful expression were also judged as being more intelligent than those with angry expressions.[5]

The Eyes

The eyes are frequently referred to as the "windows to the soul" since they are capable of revealing a great deal about what a person is feeling or thinking.

As you engage in conversation with another person, taking note of eye movements is a natural and important part of the communication process.

Some common things you may notice include whether people are making direct eye contact or averting their gaze, how much they are blinking, or if their pupils are dilated.

The best way to read someone's body language is to pay attention. Look out for any of the following eye signals.

Eye Gaze

When a person looks directly into your eyes while having a conversation, it indicates that they are interested and paying attention. However, prolonged eye contact can feel threatening.

On the other hand, breaking eye contact and frequently looking away might indicate that the person is distracted, uncomfortable, or trying to conceal his or her real feelings.[6]

Blinking

Blinking is natural, but you should also pay attention to whether a person is blinking too much or too little.

People often blink more rapidly when they are feeling distressed or uncomfortable. Infrequent blinking may indicate that a person is intentionally trying to control his or her eye movements.[7]

For example, a poker player might blink less frequently because he is purposely trying to appear unexcited about the hand he was dealt.

Pupil Size

Pupil size can be a very subtle nonverbal communication signal. While light levels in the environment control pupil dilation, sometimes emotions can also cause small changes in pupil size.

For example, you may have heard the phrase "bedroom eyes" used to describe the look someone gives when they are attracted to another person. Highly dilated eyes, for example, can indicate that a person is interested or even aroused.[8]

The Mouth

Mouth expressions and movements can also be essential in reading body language. For example, chewing on the bottom lip may indicate that the individual is experiencing feelings of worry, fear, or insecurity.

Covering the mouth may be an effort to be polite if the person is yawning or coughing, but it may also be an attempt to cover up a frown of disapproval.

Smiling is perhaps one of the greatest body language signals, but smiles can also be interpreted in many ways.

A smile may be genuine, or it may be used to express false happiness, sarcasm, or even cynicism.[9]

When evaluating body language, pay attention to the following mouth and lip signals:

- **Pursed lips.** Tightening the lips might be an indicator of distaste, disapproval, or distrust.
- **Lip biting.** People sometimes bite their lips when they are worried, anxious, or stressed.
- **Covering the mouth.** When people want to hide an emotional reaction, they might cover their mouths in order to avoid displaying smiles or smirks.
- **Turned up or down.** Slight changes in the mouth can also be subtle indicators of what a person is feeling. When the mouth is slightly turned up, it might mean that the person is feeling happy or optimistic. On the other hand, a slightly down-turned mouth can be an indicator of sadness, disapproval, or even an outright grimace.

Gestures

Gestures can be some of the most direct and obvious body language signals. Waving, pointing, and using the fingers to indicate numerical amounts are all very common and easy to understand gestures.

Some gestures may be cultural, however, so giving a thumbs-up or a peace sign in another country might have a completely different meaning than it does in the United States.

The following examples are just a few common gestures and their possible meanings:

- **A clenched fist** can indicate anger in some situations or solidarity in others.
- **A thumbs up and thumbs down** are often used as gestures of approval and disapproval.[10]
- **The "okay" gesture**, made by touching together the thumb and index finger in a circle while extending the other three fingers can be used to mean "okay" or "all right."[10] In some parts of Europe, however, the same signal is used to imply you are nothing. In some South American countries, the symbol is actually a vulgar gesture.
- **The V sign**, created by lifting the index and middle finger and separating them to create a V-shape, means peace or victory in some countries. In the United Kingdom and Australia, the symbol takes on an offensive meaning when the back of the hand is facing outward.

The Arms and Legs

The arms and legs can also be useful in conveying nonverbal information. Crossing the arms can indicate defensiveness. Crossing legs away from another person may indicate dislike or discomfort with that individual.

Other subtle signals such as expanding the arms widely may be an attempt to seem larger or more commanding, while keeping the arms close to the body may be an effort to minimize oneself or withdraw from attention.

When you are evaluating body language, pay attention to some of the following signals that the arms and legs may convey:[1]

- **Crossed arms** might indicate that a person feels defensive, self-protective, or closed-off.[1]
- **Standing with hands placed on the hips** can be an indication that a person is ready and in control, or it can also possibly be a sign of aggressiveness.
- **Clasping the hands behind the back** might indicate that a person is feeling bored, anxious, or even angry.
- **Rapidly tapping fingers or fidgeting** can be a sign that a person is bored, impatient, or frustrated.
- **Crossed legs** can indicate that a person is feeling closed-off or in need of privacy.

Posture

How we hold our bodies can also serve as an important part of body language.

The term *posture* refers to how we hold our bodies as well as the overall physical form of an individual.

Posture can convey a wealth of information about how a person is feeling as well as hints about personality characteristics, such as whether a person is confident, open, or submissive.

Sitting up straight, for example, may indicate that a person is focused and paying attention to what's going on. Sitting with the body hunched forward, on the other hand, can imply that the person is bored or indifferent.

When you are trying to read body language, try to notice some of the signals that a person's posture can send.

- **Open posture** involves keeping the trunk of the body open and exposed. This type of posture indicates friendliness, openness, and willingness.[11]
- **Closed posture** involves hiding the trunk of the body often by hunching forward and keeping the arms and legs crossed. This type of posture can be an indicator of hostility, unfriendliness, and anxiety.[11]

Personal Space

Have you ever heard someone refer to their need for personal space? Have you ever started to feel uncomfortable when someone stands just a little too close to you?

The term *proxemics*, coined by anthropologist Edward T. Hall, refers to the distance between people as they interact. Just as body movements and facial expressions can communicate a great deal of nonverbal information, so can the physical space between individuals.

Hall described four levels of social distance that occur in different situations.[12]

Intimate Distance: 6 to 18 inches

This level of physical distance often indicates a closer relationship or greater comfort between individuals. It usually occurs during intimate contact such as hugging, whispering, or touching.

Personal Distance: 1.5 to 4 feet

Physical distance at this level usually occurs between people who are family members or close friends. The closer the people can comfortably stand while interacting can be an indicator of the level of intimacy in their relationship.

Social Distance: 4 to 12 feet.

This level of physical distance is often used with individuals who are acquaintances.

With someone you know fairly well, such as a co-worker you see several times a week, you might feel more comfortable interacting at a closer distance.

In cases where you do not know the other person well, such as a postal delivery driver you only see once a month, a distance of 10 to 12 feet may feel more comfortable.

Public Distance: 12 to 25 feet

Physical distance at this level is often used in public speaking situations. Talking in front of a class full of students or giving a presentation at work are good examples of such situations.

It is also important to note that the level of personal distance that individuals need to feel comfortable can vary from culture to culture.

One oft-cited example is the difference between people from Latin cultures and those from North America. People from Latin countries tend to feel more comfortable standing closer to one another as they interact, while those from North America need more personal distance.

Roles of Nonverbal Communication

Body language plays many roles in social interactions. It can help facilitate the following:

- **Earning trust**: Engaging in eye contact, nodding your head while listening, and even unconsciously mirroring another person's body language are all signals that you and someone else are bonding.[2]
- **Emphasizing a point**: The tone of voice you use and the way you engage listeners with your hand and arm gestures, or by how you take up space, are all ways that affect how your message comes across.[13]
- **Revealing truths**: When someone's body language doesn't match what they're saying, we might intuitively pick up on the fact that they are withholding information, or perhaps not being honest about how they feel.
- **Tuning in to your own needs**: Our own body language can reveal a lot about how we're feeling. For instance, are you in a slumped posture, clenching your jaw and/or pursing your lips? This may be a signal that the environment you're currently in is triggering you in some way. Your body might be telling you that you're feeling unsafe, stressed, or any number of emotions.[14]

Remember, though, that your assumptions about what someone else's body language means may not always be accurate.

What does body language tell you about a person?

Body language can tell you when someone feels anxious, angry, excited, or any emotion. It may also suggest personality traits (i.e., whether someone is shy or outgoing). But, body language can be misleading. It is subject to a person's mood, energy level, and circumstances.

While in some cases, a lack of eye contact indicates untrustworthiness, for instance, it doesn't mean you automatically can't trust someone who isn't looking at you in the eyes. It could be they are distracted and thinking about something else. Or, again, it could be a cultural difference at play.

How to Improve Your Nonverbal Communication

The first step in improving your nonverbal communication is to pay attention. Try to see if you can pick up on other people's physical cues as well as your own.

Maybe when someone is telling you a story, you tend to look at the floor. In order to show them you're paying attention, you might try making eye contact instead, and even showing a slight smile, to show you're open and engaged.[15]

What is good body language?

Good body language, also known as positive body language, should convey interest and enthusiasm. Some ways to do this include maintaining an upright and open posture, keeping good eye contact, smiling, and nodding while listening.

Using body language with intention is all about finding balance. For instance, when shaking someone's hand before a job interview, holding it somewhat firmly can signal professionalism.[16] But, gripping it too aggressively might cause the other person pain or discomfort. Be sure to consider how other people might feel.

In addition, continue to develop emotional intelligence. The more in touch you are with how you feel, the easier it often is to sense how others are receiving you. You'll be able to tell when someone is open and receptive, or, on the other hand, if they are closed-off and need some space.

If we want to feel a certain way, we can use our body language to our advantage. For example, research found that people who maintained an upright seated posture while dealing with stress had higher levels of self-esteem and more positive moods compared to people who had slumped posture.[17]

Of course, it's verbal and nonverbal communication—as well as the *context* of a situation—that often paints a full picture.

There isn't always a one-size-fits-all solution for what nonverbal cues are appropriate. However, by staying present and being respectful, you'll be well on your way to understanding how to use body language effectively.

Full Article: https://www.verywellmind.com/understand-body-language-and-facial-expressions-4147228

Non-verbal Communication of Medical need

The Hospital Communication Book

Helping to make sure people who have difficulties understanding and /or communicating get an equal service in hospital

https://www.mencap.org.uk/sites/default/files/2016-06/hospitalcommunicationbook.pdf

Alert Cards

Alert Card

This person has a Learning Disability.

Please read their hospital traffic light assessment or Turn over for more information

Everyone is individual but it may mean:

- Communication could be difficult—consider using pictures and easy words
- Allow extra time, be patient.
- The person may not respond in the way you expect
- The person maybe anxious
- The person could have difficulty giving consent - if so consider mental capacity act

For further advice please contact the **learning Disability nurse** in your hospital

Alert Cards front and rear have been developed by Learning Disabilities Nurses in Hospital settings.
These support the use of Hospital Traffic Light Assessments.

Hospital Traffic Light

Traffic Light Assessment

Information written in purple is for patient and carers

Information to patients

This Traffic Light Assessment gives hospital staff important information about you.

Please take it with you if you have to go to hospital. Give it to the hospital staff looking after you.

Please bring a copy of your current care plans for feeding, diet, mobility, posture, epilepsy, behaviour management and your communication passport if you have them.

Information written in blue is for hospital staff

If this Traffic Light Assessment is presented to staff during an emergency admission, please contact: -

Name Relationship Tel No
Name Relationship Tel No

Nursing staff: Consider the extra risks that people with a learning disability may present and how to address these risks. This can be achieved by using a Learning Disability Risk Assessment Tool – contact your Learning Disability Nurse for more information.

Hospital Learning Disability Nurses
Contact Details

The **Hospital Traffic Light Tool** is designed to assist families in identifying and expressing their needs and priorities when seeking clinical support for their child with learning disabilities.

Prioritization: By using a traffic light metaphor, it categorizes needs into three levels:

Red: Urgent or critical needs that require immediate attention.

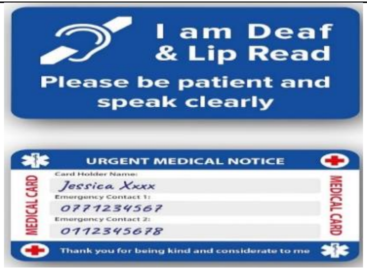
Amber: Important needs that should be addressed promptly.

Green: Less urgent needs that can be discussed during routine appointments.

Emergency Medical Information Cards

Emergency Medical Information cards are available to purchase, which hold standard medical information, along with:
Medical condition
Allergies
Other information

Standard Cards covering many common medical conditions



Standard Cards are available covering many common medical conditions and how to offer help.

Identifying cardholder Name and your Emergency Contacts.

The availability of toilets is vital to the wellbeing and quality of life for people with Crohn’s Disease and Ulcerative Colitis, users of stoma bags, etc.

Lanyards and Medical Alert Necklace or Bracelet

Lanyards holding Standard Cards covering many common medical conditions

Lanyards holding Standard Cards are available covering many common medical conditions and how to offer help. This offers an easily accessible way of carrying and displaying your information.

Medical ID Bracelets, Wallet Cards, and Lanyards

Download Association for Autism and Neurodiversity’s free wallet card and an explanation of when and how to use the wallet card.

https://aane.org/autism-info-faqs/library/safety-medical-id-bracelets-wallet-cards-and-lanyards/

Medical Alert Necklace or Dog Tags

Medical Alert Necklace or Dog Tags are available for Personalized identity, Medical Allergy and SOS Awareness of Any Condition

Medical Alert Bracelet with or without information

Medical Alert Bracelet available with standard engraving of medical conditions, which leads to faster and proper care in the event of an emergency situation.

Medical Alert Bracelet can also contain personalized information identity, Medical Allergy and SOS Awareness of Any Condition.

Hospital passports

Help in hospital - Hospital passports

A hospital passport tells the hospital about your healthcare, your learning disability, how you like to communicate and how to make things easier for you.

Getting help with your health

To create your own hospital passport, download this hospital passport document, print it off and fill it in.

https://www.mencap.org.uk/advice-and-support/health-coronavirus/health-guides

or

https://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/acute-hospitals/going-into-hospital/Traffic_Light_Assessment.pdf

You can carry your hospital passport and show it to healthcare staff at the hospital.

It can help you to get the care you need in an easier to understand way.

Guidance

https://assets.practice365.co.uk/wp-content/uploads/sites/873/2020/05/MH-LD-Traffic-Light-Assesment-Guidance-Notes.pdf

Getting help with your health

NHS

This is my

Hospital Passport

For people with learning disabilities coming into hospital

My name is:

If I have to go to hospital this book needs to go with me, it gives hospital staff important information about me.

It needs to hang on the end of my bed and a copy should be put in my notes.

This passport belongs to me. Please return it when I am discharged.

https://www.mencap.org.uk/advice-and-support/health-coronavirus/health-guides

To create your own hospital passport, download this hospital passport document, print it off and fill it in.

Hospital Passport Template example from South West London Access to Acute Group.doc (live.com)

Learning disability register - Annual health checks

Make sure you are on the *learning disability register* a list of people with a learning disability that the doctor's surgery looks after.

It will help the doctor, nurses and other healthcare staff know what support you need.

Only around 26% of people with a learning disability in England are on the learning disability register.

If people are not on this register they may not be able to get annual health checks or Covid-19 and flu vaccinations.

People on the register can get extra support from the doctor's surgery.

https://www.mencap.org.uk/advice-and-support/health/learning-disability-register

Annual health checks

- Do you have a Learning disability?
- Are you over 14?

Ask for a **free** learning disability **health check** at your local GP practice.

www.learningdisabilityservice-leeds.nhs.uk/get-checked-out

People with a learning disability often have poorer physical and mental health than other people. This does not need to be the case.

It is important that everyone over the age of 14 who is on their doctor's learning disability register has an annual health check.

An annual health check can help you stay well by talking to a doctor or nurse about your health and finding any problems early, so they can be sorted out.

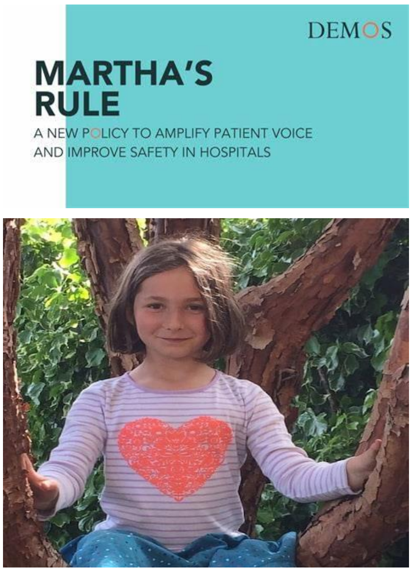
https://www.mencap.org.uk/sites/default/files/2017-06/AHC%20Easy%20Read%20Guide%20Final.pdf

Video: annual health checks for people with a learning disability

This video explains what happens during an annual health check.

https://youtu.be/ocU8XhD1kh8

Martha's Rule



The NHS announces the introduction of 'Martha's Rule' to hospitals from April 2024. The scheme will mean that seriously ill patients, their carers and care support staff will be able to request a second opinion if their condition worsens. Around 100 hospitals will be able to apply to the scheme initially.

The proposal suggests that:

all staff in NHS trusts must have 24/7 access to a rapid review from a critical care outreach team if they have concerns about a patient.

all patients, their families, carers, and advocates must also have access to the same 24/7 rapid review. Mechanisms to contact the team will be advertised around the hospital. This is Martha's Rule.

the NHS must implement a structured approach to obtain information relating to a patient's condition directly from patients and their families at least daily.

For further information about Martha's Rule, please visit the

https://www.england.nhs.uk/patient-safety/marthas-rule/#:~:text=The%20first%20phase%20of%20the,worried%20about%20a%20person%27s%20condition

NHS England gives five key elements for discharge

supporting people with a learning disability and autistic people to leave hospital.

https://www.england.nhs.uk/long-read/five-key-elements-for-discharge-supporting-people-with-a-learning-disability-and-autistic-people-to-leave-hospital/

Key Elements

- Seeing a delayed discharge as a 'harm' event
- Agree how people will work together to plan a person's discharge
- Coproduction
- Strong partnerships to support timely discharge
- Holistic, person centred care in hospital

Supporting people with learning disabilities to leave hospital

Burdett nursing discharge planner provide a booklet to be completed with the person whose discharge is being planned

https://www.learningdisabilities.org.uk/burdett/Burdett_Discharge.pdf

An easy read version of the Burdett discharge planner is available at –

https://www.learningdisabilities.org.uk/burdett/Burdett_Easy_Read.pdf

Communication Passports and Personal Information

Edit this cell to allow a user to navigate back to their communication pages, and create phrases to add to the different sections of their passport

Write chat sentences here.

This Grid will help you get to know me and how I communicate.

A Communication Passport provides a practical and person-centred approach to passing on key information about people with complex communication difficulties who cannot easily speak for themselves.

https://www.communicationmatters.org.uk/what-is-aac/types-of-aac/communication-passports/

A Communication Passport does this by:

- Describing the person's most effective means of communication, so that others can be better communication partners
- Drawing together information from past and present, from many people who know the person, and from different contexts
- Presenting the person positively as an individual, not as a set of 'problems' or disabilities

A communication passport is a way of supporting a vulnerable person with communication difficulties across transitions, drawing together complex information (including the person's own views, as much as possible) and distilling it into a clear, positive and accessible format. This helps staff and conversation partners to get to know the person with communication disabilities. They can then interact/respond consistently to help the person make sense of events and get the best out of what communication abilities they do have.

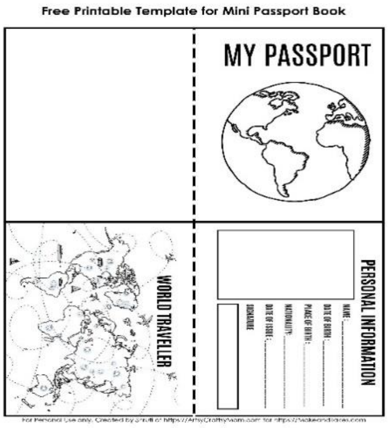
A communication passport is a vital tool in 'joined–up' inter-agency planning and working. They provide a detailed overview of an individual's needs, wishes, and sensitivities, enhancing understanding and communication during care transitions . The passports serve as a source of key information that helps healthcare professionals inform their communication, diagnosis, and treatment . They provide an overview of the behaviours that individuals display when they are well, and they contain key information based on who the individual is, how they prefer to communicate, what medications they are on, and how healthcare professionals know if they are in pain or displaying signs that they may be unwell . It promotes partnership with families, and is an excellent a way of implementing and recording consultation/participation of the individual.

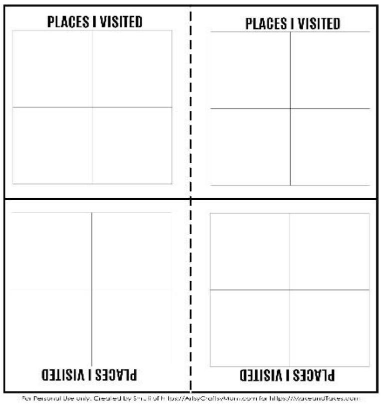
The communication passport belongs to the person – not to staff or family, though they may help him or her to use it appropriately, and update it. Passports are especially important at times of transition, when new people come into the person's life and information may not be passed on. They are also helpful when new or temporary staff or volunteers meet the person, helping them quickly to acquire key information, or for example, introducing a person to a new foster family. The process of creating a passport can help in the process of assessing people and their needs, and in identifying gaps in assessment.

A communication passport presents the person positively as an individual. It draws together information from past and present, and from different contexts, to help staff and conversation partners understand the person, and have successful interactions. It is a place where the person's preferences can be recorded. The person's preferred means of communicating is also recorded – some innovative practice uses digital film. A communication passport is a very useful way to help others understand how someone communicates.

- Use or adapt Scope's template for a child's communication passport at http://tinyurl.com/cczz13
- Read guidelines for good practice around creating and using personal communication passports at www.communicationpassports.org.uk
- Find out about 'Meet the people' CD-ROM and see how useful film can be to help people understand how people with PMLD communicate at www.mencap.org.uk/meetthepeople
- Read the Mencap Factsheet 'PMLD - multimedia profiling' www.mencap.org.uk/factsheets
- Visit the Acting Up website for more information about multimedia profiling at www.acting-up.org.uk

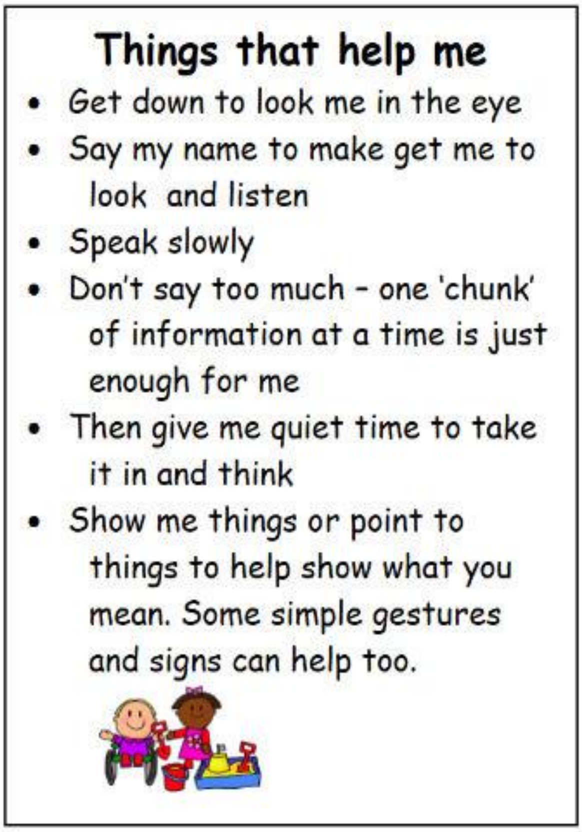
Mini CALL Passport





Lots of people like a small Passport that all fits on to one page, though obviously you can't squeeze in as much information, and it is more of a 'taster' than a full Passport. This example is in the form of a 'tri-fold' leaflet, done in Microsoft Word (these can be a real struggle to design accurately so that they fold in the right place and print the pages in the right order.....). Download here and just change the text and pictures to suit your own requirements.

https://makeandtakes.com/wp-content/uploads/Mini-Passport-Book-Template.pdf

<table>
<tr><th colspan="2">Mini Passport trifold leaflet</th></tr>
<tr><td>
Things that help me
• Get down to look me in the eye
• Say my name to make get me to look and listen
• Speak slowly
• Don't say too much - one 'chunk' of information at a time is just enough for me
• Then give me quiet time to take it in and think
• Show me things or point to things to help show what you mean. Some simple gestures and signs can help too.</td><td>A trifold brochure template is a pre-designed layout that helps you create a three-fold brochure. These templates serve as a starting point for designing brochures for various purposes, you can customize these templates by adding your own content, including text, images, and branding elements.
More Options:
https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fwww.communicationpassports.org.uk%2Ffiles%2Fcm%2Ffiles%2FminipassportEG.doc&wdOrigin=BROWSELINK
Full Article:
https://www.communicationpassports.org.uk/creating-passports/</td></tr>
</table>

One Page Profile

one page profile

Helen

What others like and admire about me

Thoughtful

Inspirational

Passionate about change

Big thinker

Supportive

What is important to me

How best to support me

https://youtu.be/fnaKnVWFh44

One Page Profile Guide - How to make a great One-Page Profile | Community Integrated Care

https://youtu.be/iDY7p2mRRXE

One-Page Profiles are a great way to share a summary of who you are and what support you need in a specific area of life through three clear elements:

what others appreciate about me,

what is important to me

and how best to support me.

https://helensandersonassociates.com/person-centered-approaches-programs/creating-one-page-profiles/

People with learning difficulties may exhibit reluctance to admit being unwell for several reasons.

Let’s explore some of these factors:

Communication Challenges:

Individuals with learning disabilities often face difficulties in expressing their feelings or symptoms. They may struggle to articulate their physical discomfort or emotional distress effectively. As a result, they might not be able to communicate their health concerns clearly.

Emotional wellbeing for young people with learning disabilities

All children and young people, including those with learning disabilities, can at times struggle with their emotional wellbeing.

For example, they may experience anxiety about going to school or feel down when they fall out with a friend.

The PERMA model

The PERMA model can provide some useful ideas of how to support a child or young person with a learning disability with their emotional wellbeing.

It was developed by psychologist Martin Seligman and identifies 5 essential elements which you can incorporate into daily life:

- Positive emotion: Encourage and support them to do things which bring them enjoyment. For example, dancing around the kitchen, going to the cinema or playing outside.

- Engagement: Prompt them to do activities which engage them and hold their attention. For example, listening to a story, going to the park with a friend or building a train set.
- Relationships: Support them to develop and maintain positive relationships. This can be individual relationships, such as encouraging them to ask another child at school if they would like to play together. It is also about finding opportunities for them to develop a sense of belonging, such as by being in a sports team, choir or nature group.
- Meaning: This is about doing things which are meaningful to them. For example, if it is important to them to be caring, they could regularly help their grandmother with watering her garden. Or if they love the family pet cat, they could be responsible for feeding them each day.
- Achievement: Provide opportunities for them to build their skills and try new things so that they can feel they have done well. This does not need to about doing well at school, although it can be. For example, if they learn how to make their own drink, they will have a sense of achievement when they help themselves without needing to ask an adult.

Other top tips - Communication

Children and young people with learning disabilities may communicate how they are feeling through their behaviour, especially if they struggle to express themselves verbally.

Remember that all behaviour is communicating something for the person. For example, if every weekday morning they refuse to get dressed, this might be because they are worried about going to school.

Physical health

Always consider whether there might be a physical health cause underlying a young person’s distress.

They may find it difficult to express if they are in pain or unwell so it is worth checking if this is impacting on how they are feeling and behaving.

Full Article: https://valuecare.org.au/6-common-barriers-faced-by-people-with-disabilities/

Challenging behaviour and learning disabilities

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Full Article: https://www.nice.org.uk/guidance/ng11/resources/challenging-behaviour-and-learning-disabilities-prevention-and-interventions-for-people-with-learning-disabilities-whose-behaviour-challenges-1837266392005

What is Challenging behaviour

‘Challenging behaviour’ is how we talk about a range of behaviours which some people with severe learning disabilities may display to get needs met.

‘Challenging behaviour’ is how we talk about a range of behaviours which some people with severe learning disabilities may display to get needs met.

Behaviours might be things like:

- **Hurting others** (e.g. hair pulling, hitting, head-butting)
- **Self-injury** (e.g. head banging, eye poking, hand biting)
- **Destructive behaviours** (e.g. throwing things, breaking furniture, tearing things up)
- **Eating inedible objects** (e.g. cigarette butts, pen lids, bedding)
- **Other behaviours** (e.g. spitting, smearing, removing clothes in public, running off)

Why do people display challenging behaviour?

Most children without learning disabilities display lots of challenging behaviour during the ‘terrible twos.’ Nut usually this doesn’t last because most 2-year olds develop a range of communication and social skills which enable them to get what they want and need more easily. Many children with learning disabilities do not develop these skills and are left with the same needs as other children of their age but are must less able to get them met. – Peter McGill, Tizard Centre, University of Kent.

Many challenging behaviours are effective ways for a person with learning disability to control what is going on around them.

How can the Challenging Behaviour Foundation help?

Behaviour described as challenging can have a significant impact, not only on the individual with learning disabilities themselves, but also family and friends caring for that person.

Full Article: https://www.challengingbehaviour.org.uk/understanding-challenging-behaviour/what-is-challenging-behaviour/

Understanding and approaching behaviours that challenge

Behaviours that challenge are behaviours defined as ‘challenging’ if they are particularly intense, frequent, or lengthy in duration – such behaviours pose a risk to the person and others and can impact on quality of life.

Understanding and approaching behaviours that challenge

Research shows that 59% of autistic individuals engage in one or more behaviours that are perceived to challenge.

Definition

Behaviours that challenge are behaviours defined as 'challenging' if they are particularly intense, frequent, or lengthy in duration – such behaviours pose a risk to the person and others and can impact on quality of life.

Some behaviours that can be observed include physical aggression such as hitting or kicking, verbal aggression such as swearing or spitting, self-injurious behaviours such as biting self and risky behaviours such as running away or stripping.

Functions of behaviour (what is a behaviour communicating?)

Behaviours that challenge occur for a reason – they serve a function for the individual. Often, the behaviours occur because the individual has difficulties with communicating their wants and needs. In order to understand the behaviour, we must understand the relationship between the individual and their environment. The environment can include situations, places, people, and activities that may trigger episodes of behaviours that challenge. By changing or adjusting the environment, this can greatly reduce behaviours that challenge.

If your child is unable to say they are feeling unwell or in pain, they may engage in behaviours that challenge. Medical causes must be explored and ruled out first with your child's GP and/or other medical professionals.

There are four main functions of behaviour:

Escape/avoidance

Some behaviours occur as a person wants to get away from something or avoid something completely. This is known as escape or avoidance. If a task is too hard, boring, or even too easy, behaviours that challenge may occur to communicate this. Examples of escape behaviours include blocking ears if they want to block out a loud noise, or running off when a task is difficult. Examples of avoidance may include having a tantrum when the school bus arrives. The tantrum results in the individual staying at home and avoiding a negative environmental factor such as a difficult lesson, an exam, or a bully.

Attention

A child or young adult may engage in behaviours to gain some form of social attention. The desire for social interaction is present and this can include even negative attention or reactions from peers and adults.

Tangible

A tangible function of behaviour includes gaining access to items or activities. A child may run towards, grab, or cry for items or a desired activity.

Sensory

Some behaviours are repeated by an individual because they provide some form of sensory feedback. They feel good, are satisfying and self-stimulating. Examples might include playing with hair, tapping your foot or chewing a pen.

Assessing the function

Antecedent Behaviour and Consequence or **ABC forms** are commonly used as a means to record instances of behaviours that challenge, writing down what happened before (antecedent), what the behaviour was, and what happened after the behaviour (consequence).

Antecedent		**Behaviour** (What is the behaviour?)	**Consequence** (What happens after the behaviour?)
Setting (Where, when, who with)	**Trigger** (What happened directly before the behaviour happened)		

Once you have a number of examples, look at the patterns, and review which function of behaviour it may be that the behaviour is communicating. Patterns you may identify include whether the behaviour occurs at the same time in the day, after a specific event or with a specific person.

Teaching alternative behaviours

Once we understand what a behaviour is communicating, we can teach an alternative way for your child to communicate their needs more effectively.

Escape/avoidance

They can be prompted to either ask for help, delay the task, ask for a break or ask for work that is more challenging. Prompting for a functional communication response can result in the demand being delivered at an appropriate/ individualised level. You could also review the task – is it too easy, too hard, or uncomfortable in some way? Look at ways to adjust the task to make this more accessible for your child.

Attention

If your child is communicating that they would like attention through their behaviours, proactively schedule in more of the preferred attention and show when this is available on a visual schedule. You can also teach your child alternative ways of accessing attention e.g., by tapping an adult’s shoulder, saying ‘excuse me’ vocally or even using adult names.

Tangible

If behaviours occur when your child wants something, proactively schedule in more of the preferred item and show them when this is available on a visual schedule. They can also be prompted to request an item in an alternative way e.g., using the PECS (Picture Exchange Communication Systems) symbol for a drink, or using their vocals to say ‘iPad’.

Sensory

If sensory behaviours occur, the person can be modelled an alternative, safe behaviour e.g., instead of biting their hand, they can bite a chewie. Only teach an alternative if the sensory behaviour is unsafe, e.g., head banging or self-biting.

Top tips for managing behaviours that challenge

There are a few things you can do to help manage behaviours that challenge:

- Identify the common triggers (antecedents) in the environment that you may be able to adjust or adapt
- Identify your child’s preferred method of communication so that they can express themselves including their wants, needs, frustrations, discomfort or pain

- Offer your child some choice so that parts of their day include engaging with events, people and activities they prefer and gaining attention from who they want
- Develop their coping strategies for when these preferred activities, events or people are not accessible – this can include breathing or counting exercises or access to fidget toys
- Model the behaviour you want to see and recognise these positive behaviours when they occur
- Respond calmly to the behaviour; this may include not commenting on the behaviour, giving your child some space or offering them a quiet space or a regulating item or activity
- If you are worried that your child is engaging in behaviours that are perceived to challenge, seek out advice and support from friends, family and professionals if necessary.

Please speak to your GP who may be able to refer you to another professional.

Full Article: https://www.beyondautism.org.uk/resource-hub/understanding-behaviours-that-challenge/

Stigma and Misunderstanding:

There is still a significant stigma associated with learning disabilities. People may fear judgment or discrimination if they admit to feeling unwell. They might worry that others will perceive them as incapable or less competent due to their disability.

Stigma and discrimination - research and statistics

Stigma and discrimination may have a significant negative impact on the lives of people with a learning disability.

The United Nations Convention on the *Rights* of Persons with Disabilities said that people with a *learning disability* have a fundamental right to full and active participation and inclusion in society (United Nations, 2006).

Up until the 1970s many adults and children with a learning disability had to stay in large institutions.

Since then, large institutions have been closed and almost all adults and children with a learning disability live in the *community*.

However, many still feel socially left out and face stigma and *discrimination* in their everyday lives (Scior & Werner, 2015).

People with a learning disability may face problems getting equal opportunities for healthcare, housing, *education*, *employment* and social pursuits.

For example:

- children with special educational needs (SEN) are twice as likely to be bullied regularly than children with no SEN (IoE London, 2014)
- in 2017/18 only 6% of adults with a learning disability known to their local authority were in paid employment in England (NHS Digital, 2018), compared to 76% of people aged 16 - 64 in the general population (ONS, 2019).

Stigma and discrimination can become internalized in people with a learning disability resulting in ‘self-stigma’.

This is associated with higher levels of psychological distress and lower quality of life (Ali et al., 2015; Pelleboer-Gunnink et al*.,* 2019).

The Disability Perception Gap

Scope identifies the difference in attitudes of non-disabled people and the reality of disabled people's experiences as the 'disability perception gap' (Dixon et al*.,* 2018).

It has been suggested that misconceptions about the capabilities of people with a learning disability may be widespread (Scior & Werner, 2015). Misconceptions and negative attitudes can be a barrier to people with a disability living the lives they want (Dixon et al*.,* 2018).

For example, just under a third (32%) of respondents in the 2017 British Attitudes *Survey* thought that disabled people are not as productive as non-disabled people. This belief may be a factor which contributes to the disparity in employment rates between people with a learning disability and the general population (Dixon et al*.,* 2018).

Increasing positive attitudes - Educational approaches

Interventions designed to challenge negative attitudes towards people with a learning disability often involve an element of education which attempts to increase knowledge of learning disability (Scior & Werner, 2015). Interventions which use educational approaches have shown some promising outcomes (Li et al*.,* 2014; Seewooruttun & Scior, 2014).

Contact-based approaches

Studies which increase contact (direct or indirect) with people with a learning disability show positive effects on attitudes (MacMillan et al., 2014; Seewooruttun & Scior, 2014; Scior & Werner, 2015). These approaches can include training delivered by people with a learning disability, tutoring programmes, experiential tasks, and indirect contact through film presentations delivered online and exposure to images that contradict stereotypes (Seewooruttun & Scior, 2014). However, studies have been limited by small sample sizes.

Studies which include both direct contact and education on learning disability have also shown positive outcomes, particularly with people who have had no prior contact with people with a learning disability (Lawson et al., 2017).

Self-advocacy

Self-*advocacy* groups allow members to address stigmatised social identities and provides opportunities to engage with ideas about rights, empowerment and greater *equality* (Clarke et al*.,* 2015; Anderson & Bigby, 2017; Fenn & Scior, 2019).

Individuals can gain a variety of benefits from self-advocacy groups, including increased confidence, changes in social and self-identity, increased social connections and *relationships*, mutual support, and increased opportunities for occupation and activities (Clarke et al., 2015; Fenn & Scior, 2019).

Full Article: https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/stigma-and-discrimination-research-and

Lack of Awareness:

Some individuals with learning difficulties may not fully understand their own health conditions. They might not recognize the signs of illness or realize when they need medical attention. Additionally, limited health literacy can contribute to this lack of awareness.

Many adults with learning disabilities have communication needs and low levels of health literacy. This makes it more difficult for them to manage their health and stay well.

Limited health literacy among adults with learning disabilities is explained by, “limited communication skills and reduced capacity to access and comprehend health information” (Baines 2010).

The impact of communication difficulties on the development of health inequalities is highlighted in the Accessible Information Standard (2016) and in the, ‘The Learning Disabilities Mortality Review Annual Report’ (2017).

One way we, as an organisation, were already trying to address this was through the provision of accessible information in the form of ‘easy read’. However, not everyone is able to access ‘easy read’ information; particularly those with little social support who do not always have people available to talk through the information with them.

https://www.rsph.org.uk/static/uploaded/f95556c0-9d3f-4d4c-b06f6e8ec5b77b9c.pdf

Dependence on Others:

Many people with learning disabilities rely on caregivers or family members for daily support. Admitting illness could disrupt their routines or create additional burdens for their caregivers. Consequently, they may downplay symptoms to avoid inconveniencing others.

When health concerns arise, it’s indeed common for people to downplay symptoms to maintain stability in their daily lives. The delicate balance between independence and reliance on caregivers can be intricate. Here are a few considerations:

1. Communication: Encouraging open communication between individuals with learning disabilities and their caregivers is essential. Creating a safe space where symptoms can be discussed without fear of disruption can foster understanding and trust.
2. Routine Flexibility: While routines provide stability, flexibility is equally important. Caregivers can adapt routines to accommodate health needs without causing undue stress. Small adjustments can make a significant difference.
3. Empathy and Patience: Caregivers play a vital role in understanding the unique challenges faced by those they support. Patience, empathy, and active listening can help caregivers recognize when symptoms are downplayed and respond appropriately.
4. Education and Support: Providing caregivers with resources and support networks can empower them to navigate these complexities. Understanding the specific needs of individuals with learning disabilities is crucial for effective caregiving.

Remember, acknowledging illness doesn’t have to disrupt routines entirely. It can lead to better care and improved well-being for everyone involved.

https://www.rcn.org.uk/magazines/History/2022/Jun/History-of-learning-disability-nursing

Fear of Institutionalization:

Historically, people with learning disabilities have faced institutionalization and segregation from society. The fear of being placed in a hospital or care facility might discourage them from seeking help. They may worry about losing their independence or being isolated from their communities.

Change can be unsettling for anyone, but it can be particularly distressing for people with learning difficulties. The prospect of medical intervention, altered routines, or unfamiliar environments may evoke anxiety.

https://www.rcn.org.uk/magazines/History/2022/Jun/History-of-learning-disability-nursing

Communication Barriers in Healthcare Settings:

Healthcare professionals may not always adapt their communication styles to accommodate individuals with learning disabilities. Complex medical jargon, rushed appointments, or lack of patience can hinder effective communication. Consequently, patients may avoid seeking medical attention altogether.

Evidence collected and examined by this review highlights the importance of effective clinician-patient communications, including the substantial benefits that patients, the taxpayer and the healthcare system stand to realise from improved communications.

In broad terms three key themes emerged clearly from the review of the research base into the impact of improvements in clinician communication:

- First, there is a substantial body of evidence demonstrating that investing in improved clinician communication with patients can make a significant positive difference to patient experience, while also benefiting both patient clinical outcomes and reducing financial demands on the health system. In other words, through introducing interventions to improve communications with patients, those patients have a better experience of their care and place less demand (or less expensive demand) upon the health service.
- Second, the evidence for all three benefits – experience, clinical outcomes and overall expenditure (‘triple impact’) – derived from investing in improved clinician communication is most compelling in the case of interventions relating to end of life care. These studies demonstrate that benefits can be realised by improving conversations about choices relating to medical intervention, care and support wishes and preferred place of death. The research suggests that patients have a much better end of life experience as a result of being given greater insight and input into the choices over their care plan. This in turn feeds into patients placing fewer demands on the healthcare system.
- Third, there is evidence that suggests other areas of clinical practice might also realise positive outcomes through improving clinician communication to patients. In these other areas there was a shortage of trials demonstrating the ‘triple impact’ (patient experience, clinical benefit, system expenditure) standard set by this research review. It is reasonable to anticipate, however, that trials in these other areas, established with requisite evaluation methodologies, might well also demonstrate that intervention to improve communication would achieve all three benefits.

Full Article: https://www.england.nhs.uk/wp-content/uploads/2021/07/SQW-NHS-England-Improving-communications-report-30June.pdf

Previous Negative Experiences:

If someone with a learning disability has encountered negative experiences in healthcare settings (e.g., feeling dismissed, misunderstood, or mistreated), they may become hesitant to seek help in the future.

Importance of identifying and meeting communication needs

Since 2016, health and care providers have been legally required to meet the Accessible Information Standard. This standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of people who use services, carers and parents of people with a disability, impairment or sensory loss. Applying this standard helps health and care providers meet their existing legal duties to make reasonable adjustments under the Equality Act 2010. We check how providers are applying the standard as part of our regulatory activity.

During our review, we found limited evidence about how hospitals were identifying, recording, flagging and sharing information. Our findings are supported by research from Healthwatch, published in February 2022, which raised concerns about how well NHS trusts are meeting the standard.

People told us that when their communication needs were met, they were more likely to have a positive experience of hospital, and be meaningfully included in their care. The quality of communication and information sharing varied both between and within the services we visited. This started from the first point of contact with the hospital and the systems to identify people with a learning disability and autistic people.

In most hospitals we visited, staff told us that GP records and referrals could provide information about a person's learning disability or autism diagnosis and/or their additional needs, including communication needs. However, access to GP records was not always possible and these records did not always include information about a person's additional needs. In addition, while hospitals had systems to flag if someone had additional needs, these were not always effective.

These gaps created the risk that staff may not recognise or be able to meet people's communication needs. This includes understanding that people with a learning disability and autistic people may communicate their distress through their actions. We heard that without this knowledge staff may not be able to recognise and make adjustments to meet their needs, such as providing quiet spaces for people who are agitated and distressed. Often, their immediate response may be to call security staff to restrain a person. In other instances, it meant that people, their family and carers had to repeat information about their needs, which staff should already have access to from care plans and other records.

Communicating with people and their carers

A key element of the Accessible Information Standard is making sure that people have access to the information they receive, and that they can understand it, as well as making sure they receive support to communicate if they need it. People with a learning disability and autistic people may also need more time to process this information.

Through our 2020 NHS adult inpatient survey, we heard that people experienced better care when staff explained things clearly and reassured them. Staff speaking with people as an equal also helped them to feel respected.

People who were well known to staff or a particular ward tended to have a better experience. Wards and clinics that saw many autistic people and people with a learning disability were also better at providing support. At one hospital, a support worker told us that staff on the medical ward, where a number of people with a learning disability were admitted, were willing to learn and appeared to have a better understanding of the needs of people with a learning disability.

However, people and carers also told us about poor experiences of staff not meeting their needs or where they felt communication could have been improved. For example, at one hospital a person told us that staff spoke too quickly and did not give them time to absorb and understand what they were saying.

These findings again reflect what we heard in the 2020 adult inpatient survey, where respondents described staff talking to them in a rude or negative way. People with a learning disability and autistic people also described being treated like children. As a result, people told us that they didn't feel respected.

Fiona's story

I needed surgery for my broken finger… On the day of the operation, they wouldn't let anyone stay with me… So I was pretty distressed around the idea of them being able to understand me as well as me understanding them. I went in at 7:30am like they said. I think I was first in the queue. They'd told me "don't have anything to eat or drink the night before. You can have a little bit of water with your medication." I took this too literally, as it turned out; I didn't have enough water in my system to go to the loo. I spent two hours in the waiting room trying to go to the loo. And nobody would explain why [they needed me to give a sample of urine] – they didn't tell me until the end. It was in case I was pregnant, which would be a problem for the operation. But I was like, I haven't had sex, so how can I be pregnant? It took them two hours to understand that I didn't understand why I had to provide a urine sample. It was just so irritating… communication wasn't there... If my mum or support worker had been there, they could've said "look, just wait and allow her time to allow it to just happen instead of making her try and go", it might have been easier. It happened about three hours later.

Issues around communication increased with the person's level of need. This ranged from staff not adjusting to meet a person's needs, to them not knowing how to interact with a person at all.

Another parent described the difficulty for staff in communicating with their daughter who is autistic, as well as having global developmental delay and a learning disability, and does not communicate verbally:

"…more could be done with the nursing staff … to [help them] understand what it means having a child with special educational needs… and can't understand instructions such as 'stay still', 'stay on the bed', and 'don't lick the floor'… at times, staff almost look a bit frightened because they don't know how to approach it. Maya is also non-verbal, so at times staff have said, 'oh, should we ask her if she wants this?' And you sort of say, well Maya is non-verbal…"

There was variation in the awareness of staff about communication aids, such as picture exchange communication (PECs) and photo journeys, and how easily staff could access these. Communication boxes contain a range of tools to help staff communicate with people. In one hospital that we visited, the contents of the boxes varied and not all the wards had them. At another hospital, we heard that staff were using their own money to stock them.

In several hospitals, not all staff knew what communication aids were available or where to find them. Some staff did not know how to use some types of communication aids, for example those that people brought in from home. In these instances, it was not clear that staff knew who would be able to help them. If staff do not have the right tools, or don't know how to use them, they will be less likely to communicate with people in the way they need. As a result, people will not be able to be involved in their care and the quality of care they receive will suffer.

Some staff spoke positively about being able to request information in an easy read format. At one hospital, staff told us that easy read literature was available online, which people could access directly or staff could do so on their behalf. At another hospital, the staff intranet provided information material about common conditions in an easy read format, along with links to useful materials from specialist organisations. The specialist learning disabilities practitioner also sometimes sent the appropriate relevant information to people in advance of their appointment.

However, in some hospitals people told us that there was a lack of easy read resources on wards. We heard this was often because of the trust's measures to address infection prevention and control. For example, one parent told us that she and others often found that when they visited their loved ones in hospital, they had not filled in the menu choice forms because they were not in an accessible format and their loved one didn't know how to fill it out.

Several hospitals told us about working with people who use services to develop accessible information. However, relying on easy read formats as an answer to meeting individual needs is not suitable for all. For some people who have a learning disability, a document of any kind does not make information more accessible. There needs to be a range of resources available to meet the needs of people with more complex communication needs.

Full Article: Experiences of being in hospital for people with a learning disability and autistic people - Care Quality Commission (cqc.org.uk)

Coping Mechanisms:

Some individuals develop coping mechanisms to manage their disabilities. Admitting illness might disrupt their established routines or coping strategies. They may prioritize stability over seeking medical assistance.

Stressful social interactions are to a degree inevitable and often can not be altered through *Problem-Focused* coping. Efforts to increase *Emotion-Focused* coping strategies are thus important to reduce the ill-effects of stressful social interactions. In this study, adults with mild ID generated a low rate of *Emotion-Focused* coping strategies. However, in contrast to our prediction, when employed *Emotion-Focused* coping was an adaptive coping strategy and the only coping strategy negatively predictive of psychological distress after controlling for the experience of stressful social interactions and the other coping strategies. Interventions aimed at increasing *Emotion-Focused* coping have been developed for typically developing children (e.g., Pincus, & Friedman, 2004; Vernon, 1983; 1989). For instance, (Vernon 1983, 1989) designed an "emotional education" program to help children identify and change negative feelings through role plays, discussion questions, and worksheets and activities. Recent research suggests that similar "emotional education" interventions aimed at increasing *Emotion-Focused* coping strategies among adults with mild ID may be effective. As previously mentioned, a large percentage of people with ID can not readily identify connections between emotions and cognitions (Dagnan et al., 2000; Oathamshaw & Haddock, 2006).

However, a growing body of research suggests that with training, adults with mild ID can be taught to regulate emotions through altering thoughts (e.g., Stenfert-Kroese, Dagnan, & Loumidis, 1997; Taylor, Novacco, Gillmer, Robertson, & Thorne, 2004). Research is needed to evaluate the feasibility of teaching adults with mild ID strategies for altering maladaptive cognitions as a way to regulate perceptions of stress surrounding negative interactions with others.

Full Article: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2838717/

Respect and promote autonomy

Autistic people often express the wish for greater autonomy – more choice in the opportunities available to them and greater control over decisions that affect their lives

"Autistic people often express the wish for greater autonomy – more choice in the opportunities available to them and greater control over decisions that affect their lives."

Autonomy, a person's control over their own life, is fundamental to being an adult member of society. With kindness and the best of intentions, those providing care to disabled people can very easily, and without realising it, undermine this important right. This can be challenging for care providers to prevent, but without personal autonomy, support staff and indeed entire health and social care systems are essentially guessing at the 'right' thing to do.

A particular challenge is that *"the rights of autistic adults to autonomy … includes the right to make decisions that others may consider unwise."*

A good service for autistic adults is one in which their rights to be adults and have control of their own lives are deeply respected. A good service for autistic children is one in which their right to be treated in age appropriate ways, experience risk and develop decision making skills is respected and promoted. A good service will support autistic children to grow into adults who understand they have power and responsibility as well as rights.

Staff, service users, family, friends and other interested people must feel confident and comfortable in recognising and challenging policies, practices and assumptions which are risk averse or undermine autonomy. Policies to encourage and enable positive risk taking in all areas of life must translate into day to day practice. Care planning and reviews should explicitly consider whether autonomy has increased and, if not, how care and support should change to increase autonomy.

"Of particular concern are interventions that may train autistic people to be unquestioningly compliant, increasing their vulnerability."

A good service for autistic people recognises that the ability to not comply is vital to effective safeguarding of both adults and children and actively encourages and respects genuine choices while ensuring that barriers to access are addressed.

"Proxy decision makers, who are not usually autistic themselves, tend to make decisions in terms of what autistic people lack. They are seldom told by autistic people what a good autistic life is like. An autistic person may not place a high value on a trait that non-autistic people consider essential, and may have, and value, abilities or affinities that have never occurred to non-autistic people."

A good service for autistic people recognises and respects autistic norms and perspectives and does not assume that what is 'normal' for non-autistic people is necessarily best for autistic people. Care plans clearly reflect and respect individual needs and preferences, including for:

- Meaningful contribution to society (and what the individual considers meaningful);
- Communication and interaction with specific individuals and in general;
- Breaks, rest and downtime;
- Balance between repetition, sameness and familiarity versus change, variety and new experiences;
- Sensory needs;

Full Article: https://nationalautistictaskforce.org.uk/publications/1-respect-and-promote-autonomy/

Half of people with a learning disability and autistic people reluctant to provide feedback on care

Thu,18 March 2021

New research from the CQC has revealed that people with a learning disability or autism are more reluctant to give negative feedback on their care in case it increases pressures on staff or services.

Debbie Ivanova, Deputy Chief Inspector of Adult Social Care, said: “Listening to the lived experience of people with a learning disability and/or autistic people has to be at the centre of how we decide to regulate and improve care. It is so important to hear their voices and allow our approach to be shaped by this in order to properly address the challenges of closed cultures and inadequate care.

“Families and people with lived experience keep telling us that it’s so much harder to speak up in services that care for people with a learning disability or autistic people, and we’ve recognised this. The work I am leading will be about improving the way we can hear from people and making sure that their experiences drive the action we take.”

CQC research also showed that people with a learning disability and autistic people are more likely to accept health and social care providers offering a lower standard of care as a result of Coronavirus and that more than a quarter (27%) of survey respondents with learning disabilities and autistic people had noticed a lower standard of safety when accessing health and social care during the COVID-19 pandemic– more than double the average.

The CQC report Out of Sight – Who Cares? Released in October 2020, found that many people with a learning disability and or autistic people are still being looked after in unsuitable hospital environments, and some are subject to high levels of restrictive practice. People with a learning disability and autistic people should be cared for either in their own home, or in their communities, with as much choice as possible.

People can give feedback on their experiences of care, or those of someone they care for, on the CQC website or through their local Healthwatch. Local Healthwatch organisations can also help you with advice and information to access the support people need.

https://www.disabilityrightsuk.org/news/2021/march/half-people-learning-disability-and-autistic-people-reluctant-provide-feedback-care

The Accessible Information Standard (DCB1605 Accessible Information)

Making health and social care information accessible
The Accessible Information Standard, formally known as DCB1605 Accessible Information, is made up of a Specification and Implementation Guidance.

From 1st August 2016 onwards, all organisations that provide NHS care and / or publicly-funded adult social care are legally required to follow the Accessible Information Standard.

The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

In August 2017, revised versions of the Specification and Implementation Guidance were issued, following a post-implementation review of the Standard:

- Accessible Information Standard Specification v1.1 (PDF)
- Accessible Information Standard Specification v1.1 (Word)
- Accessible Information Standard Implementation Guidance v1.1 (PDF)
- Accessible Information Standard Implementation Guidance v1.1 (Word)

‘Change papers’ have also been published to explain the amendments made to the ‘original’ Specification and Implementation Guidance:

- Accessible Information Standard Specification Change Paper (PDF)
- Accessible Information Standard Specification Change Paper (Word)
- Accessible Information Standard Implementation Guidance Change Paper (PDF)
- Accessible Information Standard Implementation Guidance Change Paper (Word)

The ‘Information Standards Notice’ (ISN) and other official information relating to the Standard can be found on the https://digital.nhs.uk/

Overview of the Standard

We have worked with the charity Sense to develop an animated video which provides a step-by-step overview of the Standard. The video includes subtitles and BSL interpretation.

A short summary document which provides an overview of the Standard for patients, service users, carers and parents is also available in a range of formats.

Post-implementation review

During January-March 2017 NHS England led a review of the Standard to assess impact and check that it is ‘fit for purpose’.

Over 1600 people had their say and a report of the review is available in a range of formats:

- Accessible Information Standard Review Report (Word)
- Accessible Information Standard Review Report (PDF)
- Accessible Information Standard Review Report (British Sign Language video with subtitles)
- Accessible Information Standard Review Report (Easy Read)
- Accessible Information Standard Review Report (Audio)

The report is also available on request as a paper copy, including in large print and easy read, in braille, on audio CD and BSL DVD.

The Accessible Information Standard – what you can expect from services

The Accessible Information Standard is mandatory for all organisations that provide National Health Service (NHS) or adult social care. Here's some key information about the accessible communications you should expect from services.

The standard aims to make sure that people who have a disability, impairment or sensory loss get information that they can access and understand and that they get any communication support they need from health and care services.

Organisations are required to provide alternative formats where required, such as braille, large print, and easy read. They must also support people to communicate, for example by arranging a British Sign Language (BSL) interpreter, deafblind manual interpreter or an advocate.

What do health and care organisations have to do?

1. Ask if you have any communication needs, and asked how these needs can be met.
2. Record your needs in a clear and set way and highlight these needs in your file or notes so people are aware and know how to meet them.
3. Share information about your communication needs with other providers of NHS and adult social care, when they have consent or permission to do so.
4. Deliver information to you in a way you can access and understand, with the option for communication support if needed.

What should you expect?

So, if you're speaking to a dentist, doctor, care home manager or any other provider of health and social care, here's what you can expect:

1. You should be able to contact, and be contacted by, services in accessible ways, for example via email or text message.
2. Information and correspondence should be given in formats you can read and understand, for example in audio, braille, easy read or large print.
3. You should be supported by a communications professional at appointments if this is needed to support conversation, for example, a British Sign Language interpreter.

4. Health and care staff and organisations should support you to communicate, for example, to lip-read or use a hearing aid.

What can you do if your communication needs are not met?

We know that not all services are fully compliant with the Accessible Information Standard.

If you do not receive information about our health and care in a format that suits you, you can:

1. Remind service staff that they have a legal duty to provide accessible information under the Accessible Information Standard.
2. Make an informal complaint to the nearest Patient Advice and Liaison Service which can help you to resolve issues informally.
3. Make a formal complaint. If you're thinking about making a complaint, you are entitled to support from the independent NHS Complaints Advocacy Service.
4. Share your experience with your local Healthwatch, who will feed back to local services and decision-makers, as well as feed into Healthwatch England's national advocacy work.
5. Get involved with your local Patient Participation Group or patient reference group – groups of patient volunteers which work to represent the voices of patients and improve services.

Full Article: https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/

People with Disabilities and Technology Challenges

Inaccessibility on the Web and Internet-enabled mobile technologies are threatening to exclude people who experience forms of disabilities. People with disabilities already use the Internet and other types of technologies at levels that are below those of the rest of the population. While the range of potential barriers to people who experience disabilities in the online environment is extensive, there are ways to develop and implement technologies so they are included.

An increasing number of employment, educational, communication, entertainment, civic participation, and government functions are moving either primarily or exclusively online. High levels of inaccessibility on the Web and Internet-enabled mobile technologies are threatening to exclude people who experience forms of disabilities from the information society. Unless a policy approach toward Internet accessibility for people with disabilities is reviewed and re-imagined to approach current technological and social realities - people with disabilities will have to deal with challenges related to every core element of society today.

People with disabilities already have to deal with notable challenges related to education and employment. We face a rate of unemployment that is more than the rest of the population and experience similar gaps in educational achievement. Interestingly people who experience a form of disability and are not employed want to work.

Even though there are policies relating to Internet accessibility and clear guidance for creating accessible technologies is in existence, designers and developers of hardware technologies and Web software in academia, industry, and government many times exploit gaps in existing policies to ignore the needs of people who experience forms of disabilities. The result is that the majority of Internet-related technologies are created inaccessible and cut out some or even all users with disabilities.

People with disabilities already use the Internet and other types of technologies at levels that are below those of the rest of the population. The main reason why is not due to a lack of interest or education, but because the Internet itself is unfriendly to a people who experience various forms of disabilities. The barriers they face related to access and usage differ by type and extent of the disability a person has. Since the advent of the World Wide Web, many studies have shown the inaccessibility of web sites and additional elements of the Internet. More recent studies of accessibility concerning government web sites discovered that the majority of them have major barriers to access, even though they are supposed to have been accessible for almost 10 years under law. The levels of accessibility in educational and commerce setting are worse.

Challenging Internet Interfaces

People with various abilities clearly face various challenges when accessing the Internet. People who experience visual impairments may face challenges due to a lack of compatibility of Web content with the screen reader they use, a software application that provides computer-synthesized speech output of items appearing on the screen, as well as equivalent text provided in the back-end code. Screen readers usually have issues when designers fail to place appropriate text tags on links, graphics, tables, or forms.

People who experience motor impairments, such a limited or no use of their hands or fingers, may face barriers due to a cluttered layout, links and buttons that are too small, as well as other important navigability considerations such as requiring the use of a pointing device, that may make entire functions and sites unusable for them. For people who have hearing impairments, a lack of textual equivalents of audio content can many times cut out entire portions of content from a site and interactive Web chats and additional conferencing features might be entirely impossible. People who experience communication and speech impairments may also be excluded from interactive Web chats and other conferencing features. For people with cognitive impairments such as dementia, autism, or traumatic brain injury - problems with layout, design, and navigability make the difference between the ability to use a site or not. People with specific forms of learning disabilities might face the same barriers as those with visual impairments, or people with cognitive impairments. For people with seizure disorders, the flicker rates and flash may actually jeopardize their health!

A person's experiences with the Internet many times vary depending upon the form of disability they experience. The same web site often offers opportunities for one group while excluding another entirely. A student who uses a wheelchair might find that the ability to take online educational courses makes the educational process easier for them. Yet if the course web site is not designed to be accessible for students who experience limited hand mobility - participation in the course might be limited, or even impossible.

In the same way, a web-enabled mobile device with a touch screen might appear miraculous to a person with a hearing impairment, yet be a nightmare for a person with a visual impairment if it is not designed to provide alternative methods for interacting with it. The Internet and the technologies related to it present a complex series of issues for people with disabilities, not only as an overall population, but as separate populations within the whole related to the specific disabilities people experience.

While the range of potential barriers to people who experience disabilities in the online environment is extensive, there are ways to develop and implement technologies so they are included. There are known and achievable ways to address the access barriers mentioned. Many developers of web sites and related new technologies; however, just do not consider people with disabilities when they either create or update their products. Interestingly, the inaccessible web sites and technologies that are the results of this blatant disregard of accessibility run against civil rights laws for people with disabilities. A number of the issues of inclusion and exclusion online for people with disabilities have been considered in both policy and law, yet the conceptions of disability under the law, exemptions from compliance, limited enforcement, as well as the inability of the law to keep pace with technological development, all hinder the impact that the laws have had to date.

Despite the barriers people with disabilities face, the Internet has been viewed as having incredible potential related to promoting social inclusion of people with disabilities. People with disabilities who were able to access and use the Internet have reported noticeably larger benefits from the Internet in some areas than the general population. Adults with disabilities were more likely to believe the Internet:

- Improved the quality of their lives
- Made them better informed about the world
- Helped them meet people with similar interests and experiences
- Gave them more connections to the world than the general population

At this time, some Internet technologies are significantly benefiting people with particular forms of disabilities. Other technologies are offering potential opportunities to every person with a disability.

Smartphones, while excluding a number of people with disabilities, have helped many others who experience speech, hearing or other types of communication impairments and find themselves with the ability to use the phones to communicate face-to-face more efficiently than they had been able to previously. In the same way, using video chat, people with these forms of disabilities may now converse with others over the phone in new ways.

For a larger population of people with disabilities, the Internet has a great amount of potential to create new means of interaction and communication through online communities devoted to specific forms of disabilities. A person who may never encounter someone else who experiences a similar disability in their physical environment may now interact directly with others who have similar disabilities anywhere in the world. For people whose disabilities limit their ability to leave home, the Internet has the potential to provide them with a much larger world of interaction. People with disabilities even have the choice to live their online lives as people without disabilities if they want to.

Beyond the clear communication and social benefits, the Internet offers people with disabilities an array of new ways to pursue employment and education. For people who may find it hard or even impossible to travel to a building for work or education, the Internet provides the ability to do either right from home. The potential benefits may be the best benefits in the long term for promoting social inclusion of people with disabilities given that the current levels of employment and education of people who experience disabilities is exceptionally low when compared with the rest of the population.

Due to the importance of these types of engagement with technology, the lack of equal access to the Internet will become an increasingly serious issue in the future. As more activities in the areas of employment, education, communication, and civic participation move primarily and then exclusively online, people with disabilities must be included. Inaccessible online education alone might seriously erode the ability of people with forms of disabilities to have a place in modern society.

An accessible Internet presents incredible potential to increase the inclusion of people with disabilities and facilitate online education, telework, participation in e-government, as well as the ability to form relationships that overcome barriers and challenges presented by the physical world. A new approach to public policy must be created that better eliminates the virtual barriers that are in place, ensuring that people with disabilities are not marginalized.

Full Article: https://www.disabled-world.com/disability/accessibility/websitedesign/tech-challenge.php#:~:text=People%20with%20disabilities%20already%20use%20the%20Internet%20and,a%20people%20who%20experience%20various%20forms%20of%20disabilities.

How the internet still fails disabled people

The web can be liberating for disabled adults – but a lack of training, accessibility and funding means the online world is a step too far for many.

A report released by Scope cited that disabled people could save money by learning how to use the internet. Elaine suffers from depression and anxiety. A psychiatric nurse suggested that she learn how to use a computer to keep in contact with her family so that she didn't feel so isolated. So Elaine decided to attend one-to-one tutorials at Cambridge Online. "I'm in my 50s. We didn't have computers when I was at school, so it was quite a job to teach me. I didn't even know how to use a keyboard and was afraid if I hit a wrong button, I would break it."

Since then she has learned how to type, use a search engine, send emails, save photos and make birthday cards by following the Tinder Foundation's Learn My Way courses. "My family lives in Scotland, but because of the computer I was able to see my nephew's fourth birthday pictures the next day. It's opened up a whole new life for me. If I go online I can lose myself for quite a while and it stops my mind wandering and thinking about myself.”

For 20 years, Cambridge Online has offered free courses to disabled and disadvantaged adults. Every year 300 new learners are referred to their centre where they deliver 4,000 one-to-one tutorials annually. “Most of the people who come here have never touched a computer before. Confidence that the whole thing’s not going to blow up when they touch it is what people struggle with in the beginning,” says Andrew Entecott.

There are 10 computers at the centre with adaptive hardware, touch screens, alternative keyboards and mice, and magnification and screen-reading software. “We try to sell the benefits of going online by explaining that learning how to use a mouse and keyboard can reduce the amount of time you spend on the phone speaking to the council.”

The ONS found that 27% of disabled adults had never used the internet, compared to 11% of non-disabled adults

However, using a computer is still something many disabled people struggle with. According to the Office for National Statistics, in May 2015, 27% of disabled adults had never used the internet, compared to 11% of non-disabled adults. In 2013, Ofcom said that factors beyond age and income, possibly related to the individual’s disability, contribute to limited internet access.

The Extra Costs Commission, launched by the disability charity Scope, did a year-long enquiry exploring the extra costs faced by disabled people, estimated to be on average £550 more a month. In the report released in June 2015 they cite that disabled people could save money by learning how to use the internet, for example by using cost comparison websites, yet disabled people were not online because of a lack of training, cost of equipment and the accessibility of web content.

Web accessibility is something that Ian Macrae struggles with every day. As someone with a visual impairment he uses VoiceOver software. He doesn’t often recommend people simulate a visual impairment, but recommends that if you have a Mac, to turn on VoiceOver using the Command+F5 keys. “Don’t cheat and look, but try navigating a website. I use Amazon every day to find Kindle Daily Deals. To do that I have to go through every heading before I reach what I want, then I have to go through each element within that heading to get to the list of books. The whole process of navigating a website is a long and complicated process,” he says.

However, Macrae still recommends that people with a visual impairment learn how to use the internet, saying that it can be a “liberating experience”, giving the example of doing a weekly shop online instead of the hassle of walking around a shop. He would also advise web designers to create websites that are accessible for everyone, for instance by labelling all buttons and refraining from using too much multimedia, such as Flash. “I’m not saying people shouldn’t use Flash, but they shouldn’t make their website reliant on it because if it is, the website is completely inaccessible to a [visually impaired] person.”

Some disabled adults will never see the benefits of being online. Jack lives in sheltered accommodation at Steve Woolley Court in Peterborough. He suffers from Parkinson’s disease and has no interest in the internet. “I thought it would be easy when I first heard about it, but I just get confused. I'm just so fed up with it all. Get yourself a television if you're lonely," he says. "If I was told the information I needed about my pension was online, I don't know what I'd do. I'd have to get my scheme manager to do it for me."

His scheme manager, Sean Siggee, disagrees with Jack when he says he's not interested. "Jack is interested in the internet. He's trying to get into it, but he just needs guidance." Of the 34 residents living at the sheltered accommodation, 20 use a computer. "Jack doesn't like to ask for help. He feels like he's a burden and doesn't want to bother me. It's the same with everyone. They're afraid to keep asking, but they need to because everything is going online."

The Extra Costs Commission suggest that web accessibility for disabled people isn't an area the Government's Digital Inclusion Strategy has addressed directly, nor does it offer clear accountability for improving digital accessibility. They're calling for a review of the impact of the Equality Act in improving web accessibility and taking action when service providers fail to meet their obligations.

A Cabinet Office spokesperson said: "We've put accessibility at the heart of our award-winning gov.uk website, which is compatible with a variety of accessibility tools. But we recognise that not everyone is online. That's why we'll always provide assisted digital support for people accessing government services. We're also working with the private and voluntary sectors to ensure that everyone in the UK has the basic digital skills needed to benefit from being online."

One of these partners is Go On UK. The charity was set-up in 2012 by Baroness Martha Lane Fox. Their goal is to help people realise the benefits of being online. Its Chief Executive Rachel Neaman said: "It is the combined responsibility of government, the public, private and not-for-profit sectors to help close the digital divide. 10.5 million adults, 1.2m small businesses, and over half of all charities in the UK lack the basic digital skills they need to succeed in today's digital society."

Neaman says this represents "tens of billions of pounds in losses to the economy; billions more in efficiency savings for government and businesses; and the loss of countless benefits for individuals".

Full Article: https://www.theguardian.com/technology/2015/jun/29/disabled-people-internet-extra-costs-commission-scope

Full Article: https://infoscope.gr/en/content/how-internet-still-fails-disabled-people

The Digital Divide for People with Learning Disabilities

The digital age has revolutionized nearly every aspect of our lives, offering unprecedented opportunities for communication, learning, and access to information. However, in the midst of these rapid technological advancements, a significant disparity in digital access and usage persists, particularly for vulnerable and marginalized communities. One such group facing substantial challenges in accessing and utilizing digital technologies is individuals with learning disabilities (LD).

Negative Impacts of the Digital Divide

This existing digital divide poses several significant challenges for individuals with LD.

The first way that the digital divide negatively impacts people with LD is by limiting their access to information. Digital exclusion deprives people with LD of the opportunity to access essential information and services available online. Research shows that 70% of UK websites are not compliant with accessibility standards (Scepter, 2020), and only 2% of the most popular websites in the UK meet the legal minimum requirements for accessibility (Lloyds Bank, 2020). As more information becomes digitized, those without access are further marginalized, and the minority of people with LD who do have the skills and equipment needed to access digital information are "designed out" of services (100% Digital 2020).

Another way that the digital divide negatively impacts people with LD is by reducing opportunities for social interaction. In an increasingly digital age, the internet is a vital resource for building friendships and peer networks. The lack of access to digital communication hampers social interaction and the formation of meaningful relationships in people with LD, leading to increased social isolation (Lussier-Descrober, 2018).

A third way in which the digital divide negatively impacts people with LD is by limiting education and employment opportunities. Educational resources and learning materials are increasingly moving online, therefore if people with LD lack digital access or the skills needed to meaningfully engage with digital technology then they risk being disadvantaged when it comes to accessing quality education and opportunities for skills development (Seale, 2019). Similarly, in an increasingly digital job market, limited digital access and skills may hinder the employment prospects of people with LD, contributing to higher unemployment levels within the LD community (Seale, 2019).

The final way that the digital divide negatively impacts people with LD is that it has negative knock-on effects on health and well-being. Exclusion from digital health services and telemedicine can lead to inadequate access to healthcare and therapy resources, contributing to adverse health outcomes. By failing to address this digital divide, we are widening health inequalities (Lewisham Council, 2021).

Full Article: https://www.digitalinclusionuk.org/research/the-digital-divide-for-people-with-learning-disabilities

Lost for words– improving access to healthcare for ethnic minority communities

(Healthwatch)

People with little or no English struggle at all points of their healthcare journey. Our new research shines a light on barriers and delays to care they often experience and calls for equal access for all. Clear, understandable information is vital to help you make decisions about your health and care and get the most out of services.

Clear, understandable information is vital to help you make decisions about your health and care and get the most out of services.

Our latest research shows that people who speak little or no English struggle at all points of their healthcare journey. These are often some of the most vulnerable in our society, for example, refugees and asylum seekers.

They find it difficult to register with a GP, access urgent care, navigate large healthcare premises, explain their problems, or understand what the doctor says.

Lack of interpreting support further compounds their struggles. They may not know they can ask for professional interpreters, find it difficult to access one when needed, or even understand them if interpreters don't speak their dialect.

As a result, people who speak little or no English face significant barriers and delays in receiving care, putting them at a disadvantage and contributing to health inequalities.

The NHS Act 2006 puts a legal duty on healthcare services to reduce inequalities for patients who cannot speak English "in respect to their ability to access health services; and the outcomes achieved for them by the provision of health services."

Full Article: https://www.healthwatch.co.uk/blog/2022-03-22/lost-words-improving-access-healthcare-ethnic-minority-communities

Effective communication in health and social care

In social care, effective communication goes beyond knowledge and expertise to incorporate every aspect of interaction and experience. Care workers need to have the ability to empathise when needed and talk about potentially complicated procedures and issues calmly. Confrontation or disagreements can happen, and the need to defuse these challenging situations is perhaps the most important use of strong communications skills in care.

We previously published an article talking about the importance of staff training in health and social care, but perhaps a more important discussion was had in an article about empowerment in health and social care. Written by my colleague Neoma Toersen, her article discusses the risks inherent from clients losing autonomy and feeling like they no longer have control. This is where effective communication comes in, and can help develop a rapport, build a connection, and allow proper discussion about the wants, wishes and needs of the person receiving care.

In this article we will assess communication in health and social care, with a particular focus on barriers of communication in health and social care and how we can overcome them – with special mention of our eLearning for care software. Our hope is that by reading this article you will have a better understanding of how to navigate not only the base level of conversation with patients or clients, but also the channels of communication and how to best go about engaging with people to make connections, gain insights, and ultimately improve their care.

What is communication in health and social care?

Healthcare workers use communication skills (such as those developed by our online communication training) to provide emotional support to patients, protect patient privacy, and to teach new workers how to provide care. The quality of communication in health and social care is crucial because it affects the quality of care that patients receive.

Examples of health and social care settings where effective communication is necessary include hospitals, GP surgeries, dentists, nursing homes and social care support centres.

When health and social care workers communicate well with each other, and with their patients and their families, patients feel more comfortable and supported. As you probably already know, people should have control over their own care and how it is delivered, in so far as they are able to.

Examples of health and social care communication methods

There are many effective methods of communication in health and social care. These include verbal, non-verbal, written and visual communication.

1. Verbal communication

This is the most common form of communication and involves communicating through speech. It is important to use clear and concise language when communicating verbally, and to make sure that you are speaking at a pace that the other person can understand. Even this description could be worded simpler to say “keep things jargon free until you know a person’s capability to understand.”

2. Non-verbal communication

Body language, facial expressions and physical gestures are all manners of communicating non-verbally. It is important to be aware of your own non-verbal communication, as well as the non-verbal communication of others, in order to effectively communicate. Words only go so far.

3. Written communication

Notes, emails, letters and reports. All are written, but while it’s important to use clear and concise language when writing – just as with the speech – it’s more important to use proper grammar and punctuation. Leave no room for error, and if in doubt utilise tools like Grammarly to help.

4. Visual communication

Visual communication is things such as charts, graphs and diagrams. If a visuals isn’t easy to understand, it’s not worth using, so factor that in when you’re making a graphic. You are the expert in this case, imparting knowledge. The visual is the short version to hit the key points and help the reader develop an initial understanding.

Why is communication important in health and social care settings?

Help them feel in control

As you can expect once people enter the care system, they can feel like they’ve lost control of their lives. Simple things they took for granted become harder, day to day tasks might be dictated by a nurse or carer. Good communication in health and social care can avoid the person feeling like this, creating the opening to use their voice more and have their say on their care service.

Person-centred care is a big target within the UK healthcare system. People should always have a say in their own care and how it is delivered if they are able to. Even if your organisation is giving people that control though, poor communication skills can make them think the opposite and undermine your person-focused approach.

Ease their anxiety

Anxiety and depression in care homes is more prevalent than ever before, and a lot of that comes from loneliness. Articles in national papers like the Financial Times and regionals like the Lancashire Evening Post tell stories of loneliness amongst people of all ages, while the BBC even reported on how virtual reality escapism is helping people socialise.

The UK gov website states that "40% of older people living in care homes are affected by depression", whilst the British Geriatrics Society reported back in 2018 about the increase in depression for care home residents.

Reduced independence in social care is something we've also written about here at Access, but it's more than just that. Isolation, reduced socialisation with family and friends, more medical needs… all of these are stress factors. Proper communication in health and social care settings addresses these and can mitigate a lot of the fear surrounding the change in circumstances.

Good awareness lets carers notice if the characteristics of anxiety issues are present. Does the person feel nervous, are they breathing quicker, are they more irritable? This then feeds into good communication as a way to keep an individual calm. Care worker is as much about the soft skills of talking and engaging with a person as it is checking their health and assisting eating or cleaning. It's important to engage at the client's pace; let them talk and choose your words carefully to reduce these anxieties and build up their confidence.

Save money and avoid errors

One of the barriers to communication in health and social care is money – as it is with most things in life. Money can limit the channels available to communicate with clients, as well as with colleagues. Poor communication as an organisation is as detrimental if not more so than issues with a client.

Poor communication skills can lead to errors such as mistakes on tests and prescribing and administering the wrong medicines. An article from 2014 by The Guardian newspaper cited former UK health secretary Jeremy Hunt and stated that mistakes in the NHS were costing up to £2.5 billion per year – a damning figure that has hopefully been reducing ever since.

What communication skills does a care worker need?

Care workers need a select set of skills to be successful when communicating. These develop during their time in care, but must always be present in their role. Some examples include:

Verbal communication

Care workers need to be able to communicate verbally in order to respond to questions, find out about patients' problems or needs, and to draw out all the information they need from a service user as they can come across barriers.

Examples of verbal communication in health and social care include:

- discussing a treatment plan with a patient

- giving instructions to a care worker
- communicating with a colleague about a client
- discussing a problem with a supervisor
- participating in a team meeting and group discussions

Active listening

Active listening is a key communication skill that is taught to health and social care professionals. It is the process of fully attending to another person, using both nonverbal and verbal cues, in order to check understanding of the patient. This requires the healthcare worker to focus entirely on the speaker. Good active listening skills can help to build trust and rapport, resolve conflict, and improve overall communication.

Non-verbal communication

Using non-verbal communication is key. There may be times the service user struggles verbally. Understanding their requirements without the need to be verbal and making sure they understand is important for their care.

Considering cultural differences

Understand cultural differences and how they might impact communication.

These skills may take time to develop as experience and exposure are key, but a carer needs to have natural empathy and be a ‘people person’ - which is something a lot of residents require in their day-to-day lives in care.

Full Article: https://www.theaccessgroup.com/en-gb/blog/hsc-effective-communication-health-and-social-care/

Communicating to achieve citizenship

Citizenship is a practical and achievable goal for all of us

We can be equal and different by becoming citizens and supporting others to achieve citizenship.

Citizenship is a funny word - and it can have several meanings - but it is a useful word, because it can be used to describe how human beings can live together - with justice and mutual respect. Citizenship means:

- **Being respected** - being able to hold your head up high and getting respect from those around you
- **Being equal** - citizens all have the same fundamental worth or dignity, they don’t believe that just because someone has more money, power or a better-paid job that this makes them a better person
- **Being different** - citizens are not identical, they have many different gifts which they bring together to build a better world

Citizenship is important because it reminds us that we can each live a good life, in our own way, while also being able to live together with mutual respect. Citizenship means rejecting the idea that people’s worth can be measured by money, power, fame, intelligence or any of the other ways that make people different and which some people imagine define ‘what is important’.

The seven keys to citizenship

Of course this an ideal, and citizenship is not achieved by simply talking about it, wishing it or even demanding it (although all these things may help). Citizenship is something we build - together - for each other.

And there are real ways of achieving citizenship:

1. **Freedom** - being a citizen means being in control of your own life - being able to make decisions, make mistakes, make your own way. For people with significant communication difficulties this also means lots of thoughtfulness, love and attentiveness. But everyone can be in control - especially if we listen to those who know and love the person most.
2. **Direction** - being a citizen means having a life of meaning - your own meaning. When our lives don’t fit our passions, interests and abilities we are diminished - but if we can find a path that is right for us then we help other people to see us with respect.
3. **Money** - money is important, but may be not for the reason we all think. Money gives us the means to be independent, to set our own course and to achieve our own goals. But too much money is an obstacle to citizenship - mad consumers and millionaires aren’t citizens - but citizens do pay their own way.
4. **Home** - we all need a place we can call our home, not just a shelter, but a place where we can have privacy, where we can be with those we love, where we belong. When we have no home we appear almost rootless and disconnected - when we say someone has gone into ‘a home’ we mean they’ve lost their home.
5. **Help** - we live in a world where we imagine that needing help is bad, even though we all need help everyday and the giving and receiving of help from others is the key to a good society. The challenge today is to get help without having to give up your citizenship
6. **Life** - and it is by giving something back to our community that we can really help others to understand our worth. And there are so many more ways to give back than we think. We can contribute by just being there, by buying, by joining in, by working, by laughing or even by crying. But we cannot contribute if we are absent.
7. **Love** - the beginning and the end of citizenship is found in love. Through meeting, working with and joining in with other people we can form relationships, friendships, find lovers and make a family. Love is also the best guarantee of bring into existence a new generation of citizens to help build a better world.

Full Article: https://citizen-network.org/library/keys-to-citizenship2.html

A Guide to Carers and Confidentiality

(Nottinghamshire Healthcare NHS Foundation Trust)

Who is a carer?

A carer is someone of any age who provides regular unpaid support to another person who could not manage without help. Caring may include physical, practical or emotional support.

What is confidentiality?

Confidentiality means keeping information about patients safe. There are rules about confidentiality that we all have a legal responsibility for. These include asking patients what information we can share about them, who we can share that information with and how we share the information.

The importance of sharing information

Sharing information between colleagues and a carer is vital to the care and treatment of our patients

A carer is often the person that knows the patient best.

A carer's wellbeing can be improved if we work together.

It helps carers to deal with difficult situations if they are given information about care plans, health conditions, medication and dealing with a crisis.

Information that can be shared

The UK General Data Protection Regulation and the Data Protection Act (2018) govern how the Trust processes personal information. They also provide patients certain rights about how their information is processed, including deciding whether they want their information to be shared. **Confidentiality never prevents contact between colleagues and carers and does not prevent colleagues from receiving information.**

Carers will be supported and encouraged to:

- Share information with colleagues about the patient
- Receive general information about;
  1. the service and its treatments
  2. health conditions
  3. help and support available for carers
  4. coping with stressful situations
- Receive an explanation why specific information can't be shared
- Know who to contact to express concern about the patient, in an emergency or out of hours

Barriers to the sharing of information

Care works best when patients, carers and colleagues work together.

At times, patients may not want to share particular types of information and their wishes must be respected by colleagues.

Colleagues will agree with the patient the type of information that can be shared and who it can be shared with.

Colleagues will advise carers if they are unable to share information with them.

- **General information** - for example, as described in the previous section. This can be shared without any permission.
- **Sensitive, confidential information** - for example, information about a patient's health and care including their diagnosis and care plans, sexual orientation, religious beliefs. Seek permission to share issue by issue and review regularly.

If colleagues feel there is a **safeguarding risk** to the patient by sharing or not sharing information, they have a duty of care to follow the Trust Safeguarding policy.

The duty of confidentiality may be lawfully breached when:

- The law requires it
- It is in the public interest-typically to avert a risk of serious harm to individuals (including the patient) or the public
- It is in the 'best interests' of the patient to share the information. For example, if a patient is unable to consent to their data being shared at that time

Good practice to overcome the barriers

To make sharing information better and easier colleagues will:

- Talk to the patient about:
  1. Why it is important to share information ?
  2. How sharing information can help them?
  3. What information they want shared?
  4. Who they want to share information with?
- Colleagues will record a patient's decision about sharing their information in their medical records.
- Colleagues will revisit the patient's decision with them at regular intervals.
- Colleagues will routinely identify carers at first contact/assessment and talk to carers about confidentiality and explain if they can not share some information

Full Article: https://www.nottinghamshirehealthcare.nhs.uk/iev-guide-to-carers-and-confidentiality

Other information is available at: www.nottinghamshirehealthcare.nhs.uk/families-and-carers

Communication with carers in order to inform due to confidentiality

In order to find the right balance when sharing information with all parties, staff must consider the carer's, as well as the service user's own health needs, cultural expectations, willingness and capability.

Confidential health-related personal information is shared between care professionals such as doctors and nurses involved in a service user's care, so that they get the safest and highest possible quality clinical care. In addition, staff need to include carers in the extended care and support team. Carers' roles require them to be well informed to be able to provide the essential support that service users need. Effective care and better clinical outcomes rely on this three-way partnership between people who experience mental health problems, their families and carers, and our staff.

Duty of confidentiality

Service users have a right to expect that information about them will be held in confidence. This is central to the trust between them, their professional care team and their carer. Carers also have the same right to expect that the information they provide will be held in confidence by the professional care team and that this is equally crucial to maintain the trust between all parties.

Duty to share information

Doctors, nurses and other members of the care team have a duty to share information about the care treatment, medication and other important information about a person's health, in order to provide the safest and best clinical care possible.

Good communication

Carers are more likely to recognise subtle changes at an early stage of illness or relapse, as they know the service user when they're well. This information can often prove crucial to ensure early access to appropriate service and intervention by professionals. Wherever possible, communication between staff and carers must start as early as possible. Staff must avoid professional jargon and communicate clearly. In most situations face-to- face communication is better, in order to develop a mutually trusting and beneficial working relationship. Carers often value education and encouragement to learn what effective support and services may be available for their relatives.

Consent to share information

Confidential information about a service user should only be shared with their explicit permission. If the service user doesn't give permission, confidential information can only be disclosed in exceptional situations, such as where the service user's, or others' health and wellbeing is under serious risk, or where there is a public interest or legal reason for disclosure without consent. The care team should always revisit a service user's refusal to share information with their carers. Many service users often agree to sharing information with carers when their condition improves. The decision to override duty of confidentiality in the best interest of the service user must always be made by staff authorised to make a disclosure, following the strict guidelines laid out in the trust's confidentiality policy

Full Article: https://carers.org/downloads/information-sharing.-slam-carers-and-confidentiality-2018-(002).pdf

Obtaining Patient Feedback to improve quality of patient-centred care

Organisations should embrace all forms of feedback (including complaints and unsolicited feedback) as an opportunity to review and improve care.

Both staff and patients want feedback from patients about the care to be heard and acted upon and the NHS has clear policies to encourage this. Doing this in practice is, however, complex and challenging. This report features nine new research studies about using patient experience data in the NHS. These show what organisations are doing now and what could be done better. Evidence ranges from hospital wards to general practice to mental health settings. There are also insights into new ways of mining and analysing big data, using online feedback and approaches to involving patients in making sense of feedback and driving improvements.

Large amounts of patient feedback are currently collected in the NHS, particularly data from surveys and the NHS Friends and Family Test. Less attention is paid to other sources of patient feedback. A lot of resource and energy goes in to collecting feedback data but less into analysing it in ways that can lead to change or into sharing the feedback with staff who see patients on a day-to-day basis. Patients' intentions in giving feedback are sometimes misunderstood. Many want to give praise and support staff and to have two-way conversations about care, but the focus of healthcare providers can be on complaints and concerns, meaning they unwittingly disregard useful feedback.

There are many different reasons for looking at patient experience feedback data. Data is most often used for performance assessment and benchmarking in line with regulatory body requirements, making comparisons with other healthcare providers or to assess progress over time. Staff are sometimes unaware of the feedback, or when they are, they struggle to make sense of it in a way that can lead to improvements. They are not always aware of unsolicited feedback, such as that received online and when they are, they are often uncertain how to respond.

Staff need the time, skills and resources to make changes in practice. In many organisations, feedback about patient experience is managed in different departments from those that lead quality improvement. Whilst most organisations have a standardised method for quality improvement, there is less clarity and consistency in relation to using patient experience data.

Staff act on informal feedback in ways that are not always recognised as improvement. Where change does happen, it tends to be on transactional tasks rather than relationships and the way patients feel.

Full Article: https://evidence.nihr.ac.uk/collection/improving-care-by-using-patient-feedback/

Communication is key to getting complex discharge right

Consenting to Treatment: Mental Capacity Act 2005

The Mental Capacity Act (2005) (MCA) provides a legal framework for supporting individuals who may lack the capacity to make some decisions for themselves. This may be due to a learning disability, mental health problem, brain injury, dementia, alcohol or drug misuse, side effects of medical treatment or any other illness or disability.

It is useful to attach a copy of the five principles to any Mental Capacity Assessment, to be reviewed prior to the assessment in order to ensure the assessment is only completed if necessary and that appropriate support is put in place, while also respecting the individual and their Rights

Principle 1: Presumption of Capacity

By presuming capacity, we are respecting the individual's rights to make a decision for themselves. We should never assume that because a person has a cognitive impairment, that they are unable to make a decision that will impact on their daily life.

If we have reasonable doubt that their impairment is affecting their ability to make a particular decision, it is our responsibility to demonstrate their Capacity or Incapacity for this specific decision.

It is important to note here that if a person is suspected to be under duress and/or their decision-making impacted by other people, then this does ***not*** fall under the Mental Capacity Act (2005). Rather, it should be raised via other channels, including multi-disciplinary meetings with appropriate teams, and safeguarding if necessary.

Principle 2: Individuals have the right to be supported to make their own decision(s)

This refers to *all* reasonable adjustments to support understanding, enable retention, facilitate communication and weigh-up a specific decision. To make assessments accessible and inclusive, we should carefully consider our approach to engagement, whether the user needs to be supported with assisted or augmentative communication aids, and maybe even consider including breaks in the assessment to make the process easier for them.

Other factors to consider include ensuring the assessment is conducted at the best time of day and that it is held in a quiet, low-stimulus environment to minimise distractions. If communication aids are required, these should be prepared in advance, and the format of questions adjusted based on the service user's needs – for example, if braille resources are required, or even a translator.

This list is by no means exhaustive, and will vary very much on a case-by-case basis.

It is important to bear in mind here that the steps we take to support capacity ***should in no way*** lead the individual towards a particular outcome. The service user should be provided with all available options and should not be influenced by the preference of others.

Principle 3: Individuals have the right to make 'unwise' decisions

The Mental Capacity Act is designed to uphold and promote a person's rights. Therefore, if they are judged to have capacity to make a specific decision, then it is not our role to judge an individual's choices, even if we perceive them to be unwise.

For example, if a person has physical health challenges and has had several falls at home, the 'preferred' option might be to suggest they move to a supported living arrangement. However, if they are able to demonstrate that they have capacity to make the decision to stay living in their own home, then they have every right to make this decision for themselves, even if we might consider it unwise.

In this case, then no Best Interest Decision is required. Equally, someone with Lasting Power of Attorney (LPA) would ***not*** be able to overrule their decision and act on their behalf.

Principle 4: If a person has been found to lack capacity for a specific decision, then any decision made on their behalf must be in their Best Interest

A Best Interest Decision must follow a specific process for all complex decisions, such as treatment, accommodation, care etc. It should involve relevant health care professionals as well as family members, those granted LPA, and others. In the Best Interest meeting, the group should consider all the options for the individual, weighing up what the person would want, what the impact could be with each decision and what the Least Restrictive Options might be. The meeting should then lead to a join conclusion as to the best way forward.

If there is any disagreement, then further meetings should be held in order to reach a mutually agreed decision on what would constitute the individual's Best Interest. If no Best Interest Decision can be reached, then the case should proceed to the Court of Protection.

Principle 5: If a person has been found to lack capacity for a specific decision, then any decision made on their behalf must be the Least Restrictive Option

In the course of decision-making, we should never make a 'blanket decision' that applies to everyone. Not only does a blanket decision presume that 'one size fits all', but it also removed aspects of person-centred care and may even impede their Article 5 rights to Liberty.

For example, if a person is walking somewhere purposefully and seeking to leave, then it can be easy to assume that they 'must' need medication in order to calm their presentation. However, this is quite a serious presumption to make, and really the purpose of their actions should be explored. It may be for example that they require the toilet, that they are seeking out a family member, that they are completing a habitual pattern from the past or that they are in some way either under- or over-stimulated.

It is therefore really important that each case is treated independently, and that all steps are taken to get to the bottom of why someone is behaving in a particular way. This then means that appropriate and proportionate support can be provided in a person-centred way, ensuring medication is the ***last resort*** as a form of chemical restraint. Other examples may include access to kitchen facilities to make one's own drinks; access to smoke or vape; support for personal care; medication content; observations and monitoring etc. While each case will present its own unique challenges, any decision made on behalf of a vulnerable person should be the *least restrictive option*. Safe access to the community should be available for all.

https://mental-capacity.co.uk/five-key-principles-mental-capacity-act/

https://www.mencap.org.uk/sites/default/files/2016-06/Mencap%2527s%20Guide%20to%20the%20Mental%20Capacity%20Act.pdf

Supporting People with LD and Autism to Consent

Share2 Care - East Lancashire Hospitals NHS Trust A Focus on Learning Disabilities and Autism

Autism to Consent Both the Mental Capacity Act (2005) and Disability Discrimination Act (1995) emphasise the importance of supporting and enhancing an individual's ability to consent to care or treatment. In doing this it may be necessary to adapt the manner in which you convey information regarding the proposed care or treatment.

People who have learning disabilities and autism may need special consideration to ensure that they receive care and treatment which meets their specific needs and maintains their safety while they are patients in our care at ELHT.

The National Patient Safety Agency (2004) concluded that patients with learning disabilities are particularly vulnerable when in acute hospital settings leading to varying degrees of harm as a result.

"People with a learning disability, autism or both often have poorer physical and mental health than other people. We know that we need to understand why so that we can make a difference to people's lives". (NHS England, 2018)

People who have learning disabilities and autism often have a number of complex needs. These may include impairments in functional skills, communication and additional sensory impairments. In addition they may also have multiple disabilities or complex health problems and are therefore more likely to use health services (including acute hospital services) on a regular and frequent basis.

How will I know if my patient has a learning disability?

Family, carers or the patients themselves may tell you that they have a learning disability. It may also be documented on the electronic patient systems or in the case notes that the patient is known to have a learning disability. This can sometimes be confused with learning difficulties so you may need to confirm this diagnosis.

You may notice however that the person:

- Has difficulty understanding and retaining new or complex information
- Will require that you use simple language and explain things that may be unfamiliar
- May rely on others to meet some or all of their basic needs or to maintain their safety
- Has difficulty following instructions
- Has difficulty understanding abstract concepts such as time or directions
- Repeats phrases in conversation without expanding on the content

Learning disability and autism do co-exist but can also be mutually exclusive.

Improved outcomes can be achieved for patients with learning disabilities and/or autism by effective planning, communication and relationship-building. This is likely to reduce the number of appointments missed or failed attempts at procedures.

Preparation

Consideration should be given to what preparation a patient with complex needs might require in order to achieve good outcomes and a positive experience. For example, patients may be put at ease if supported to visit the ward or department ahead of their appointment or have the opportunity to see the equipment that will be used. Always be ready with everything that you will need so there will be no interruptions or distractions once you start your procedure.

Communication

People who have a learning disabilities/autism are likely to have difficulty understanding abstract concepts or have limited understanding of the treatments being proposed. Showing the person before you do the procedure can help alleviate anxiety. Many individuals will require such preparation and information in order to make an informed decision and to consent to treatment. It is likely that any intervention will take longer to complete. Remember that, giving time and communicating effectively will improve that experience for the patient.

Relationship

Developing a relationship is vital when the person is anxious. It is sometimes helpful to have two people attending to the person, one to provide reassurance and distraction and the other to complete whatever intervention is needed.

Capacity to consent

Assessment of capacity to consent to care and treatment is essential for the planning of ongoing care and decisions about how to manage care effectively. This may include decisions about having blood taken, cannulation for Infusion of fluids and medications and alternative feeding such as insertion of a nasogastric tube.

Restraint and/or Sedation

Use of any type of restraint - physical or chemical - should be a last resort. In emergency situations the Mental Capacity Act (2005) allows for proportionate restraint to be used. In any other situation, the use of restraint must be discussed and recorded as part of a best interest meeting with the family/carers.

Support

If it is clear that the person is resistant to intervention, please seek advice and support from the Specialist Nurse for Learning Disability and Autism.

Supporting People with LD and Autism to Consent

Both the Mental Capacity Act (2005) and Disability Discrimination Act (1995) emphasise the importance of supporting and enhancing an individual’s ability to consent to care or treatment. In doing this it may be necessary to adapt the manner in which you convey information regarding the proposed care or treatment - for example by using simple language or accessible health information.

You should also consider that some individuals may require longer to process information and to come to a decision. You may have assessed that the person lacks the ability to make a decision at this time; you may consider if it is appropriate or safe to delay treatment to allow time for work to be done to enhance the individual’s ability (capacity) to make a decision regarding the proposed treatment/s.

Care or Treatment in an Individual’s Best Interests

It is essential that you endeavour to discuss your decision to provide treatment in best interest with a person who knows the patient well. Ideally this should be the next of kin or close family member. It is not appropriate to ask employed carers to enter into best interest discussions or sign consent forms. When a person does not have a family member of friend to consult you must refer for an Independent Mental Capacity Advocate (IMCA).

https://elht.nhs.uk/application/files/9415/7192/9621/Share_2_Care_Learning_Disabilities_and_Autism_-_FINAL.pdf.

Decision-making and mental capacity NICE guideline

Supporting decision-making

'A person is not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success.' (Principle 2, section 1(3), Mental Capacity Act 2005)

Principle 2 of the Mental Capacity Act 2005 requires practitioners to help a person make their own decision, before deciding that they are unable to make a decision. Supporting decision-making capacity effectively requires a collaborative and trusting relationship between the practitioner and the person. It does not involve trying to persuade or coerce a person into making a particular decision, and must be conducted in a non-discriminatory way. It requires practitioners to understand what is involved in a particular decision, and to understand what aspects of decision-making a person may need support with, and why.

This may mean helping a person with their memory or communication, helping them understand and weigh up the information relevant to a decision, or helping to reduce their distress. Various ways to support decision-making capacity are described in Chapter 3 of the Mental Capacity Act 2005 Code of Practice.

1.1.12 Find out from the person how they want to be supported in decision-making in accordance with principle 2 of the Mental Capacity Act 2005. If they would like someone to support them, find out from the person who needs support who this should be. Be aware of the possibility that the nominated person may be exercising undue influence, duress or coercion regarding the decision, and take advice from a safeguarding lead if there is a concern.

1.1.13 At times, the person being supported may wish to make a decision that appears unwise. As confirmed by the third key principle of the Mental Capacity Act 2005, a person is not to be treated as unable to make a decision merely because he or she makes an unwise decision.

1.1.14 Practitioners supporting a person's decision-making should build and maintain a trusting relationship with the person they are supporting.

1.1.15 Practitioners should take a personalised approach, accounting for any reasonable adjustments and the wide range of factors that can have an impact on a person's ability to make a decision. These should include:

- the person's physical and mental health condition
- the person's communication needs

- the person's previous experience (or lack of experience) in making decisions
- the involvement of others and being aware of the possibility that the person may be subject to undue influence, duress or coercion regarding the decision
- situational, social and relational factors
- cultural, ethnic and religious factors
- cognitive (including the person's awareness of their ability to make decisions), emotional and behavioural factors, or those related to symptoms
- the effects of prescribed drugs or other substances.

They should use this knowledge to develop a shared and personalised understanding of the factors that may help or hinder a person's decision-making, which can be used to identify ways in which the person's decision-making can be supported.

Providing information to support decision-making

1.1.16 At the start of the decision-making process, practitioners should clearly determine what information they need to cover the salient details of the decision they are supporting the person to make. This will depend on the nature and complexity of the decision itself.

1.1.17 Offer tailored, accessible information to the person being supported. This should be about the process and principles of supported decision-making as well as about the specific decision.

1.1.18 When providing the person with information to support a particular decision:

- do so in line with the NHS Accessible Information Standard
- support them to identify, express and document their own communication needs
- ensure that options are presented in a balanced and non-leading way.

1.1.19 Record the information that is given to the person during decision-making. Give the person an opportunity to review and comment on what is recorded and write down their views.

1.1.20 Consider tailored training programmes for the person, to provide information for specific decisions – for example sexual education programmes and medication management.

Supporting decision-making

1.1.21 Support people to communicate so that they can take part in decision-making. Use strategies to support the person's understanding and ability to express themselves in accordance with paragraphs 3.10 and 3.11 of the Mental Capacity Act Code of Practice.

1.1.22 Involve significant and trusted people in supporting decision-making, in line with the person's preferences and:

- have due regard for the principle of confidentiality set out in paragraph 3.15 of the Mental Capacity Act Code of Practice
- ensure that this support is free from coercion or undue influence, for example that it does not undermine the person's ability to understand, retain, use and weigh information and express a choice.

If there are no significant trusted people, or no-one willing to take on this role, think about involving an advocate.

1.1.23 Practitioners should be aware of the pros and cons of supporting decision-making and be prepared to discuss these with the person concerned. The benefits could include increased autonomy, being better informed and sharing decisions with people interested in their welfare. However, practitioners should also be aware that talking about potentially upsetting issues including declining health or end of life can be potentially distressing, and a person may feel overwhelmed with having to make a difficult decision at a difficult time and having to deal with possibly conflicting opinions.

1.1.24 Give people time during the decision-making process to communicate their needs and feel listened to. Be aware that this may mean meeting with the person for more than 1 session.

1.1.25 Practitioners should increase the person's involvement in decision-making discussions by using a range of interventions focused on improving supported decision-making.

1.1.26 Where possible and relevant, ensure that the same practitioner provides continuous support to the person as they make different decisions at different points in time.

1.1.27 Health and social care practitioners should refer to other services (for example speech and language therapy, clinical psychology and liaison psychiatry) that could enable the person to make their decision when their level of need requires specialist input. This is especially important:

- when the person's needs in relation to decision-making are complex
- if the consequences of the decision would be significant (for example a decision about a highly complex treatment that carries significant risk).

1.1.28 Practitioners should make a written record of the decision-making process, which is proportionate to the decision being made. Share the record with the person and, with their consent, other appropriate people. Include:

- what the person is being asked to decide
- how the person wishes to be supported to make the decision
- steps taken to help the person make the decision
- other people involved in supporting the decision
- information given to the person
- whether on the balance of probabilities a person lacks capacity to make a decision
- key considerations for the person in making the decision
- the person's expressed preference and the decision reached
- needs identified as a result of the decision
- any further actions arising from the decision
- any actions not applied and the reasons why not.

1.1.29 Organisations should ensure they can demonstrate compliance with principle 2, section 1(3) of the Mental Capacity Act 2005 by monitoring and auditing:

- person-reported outcomes, including the extent to which the person experiences collaboration and empowerment when making important decisions and the extent to which they experience support for their decision-making
- practitioner-reported outcomes, including the frequency and quality of steps they have taken to support decision-making
- process outcomes, including the frequency and quality of formal recording of steps taken to support decision-making and the use of overt and covert coercion during decision-making.

Full Article: https://www.nice.org.uk/guidance/ng108/resources/decisionmaking-and-mental-capacity-pdf-66141544670917

Assessing capacity Consent to treatment

All adults are presumed to have sufficient capacity to decide on their own medical treatment, unless there's significant evidence to suggest otherwise.

What is capacity?

Capacity means the ability to use and understand information to make a decision, and communicate any decision made.

A person lacks capacity if their mind is impaired or disturbed in some way, which means they're unable to make a decision at that time.

Examples of how a person's brain or mind may be impaired include:

- mental health conditions – such as schizophrenia or bipolar disorder
- dementia
- severe learning disabilities
- brain damage – for example, from a stroke or other brain injury
- physical or mental conditions that cause confusion, drowsiness or a loss of consciousness
- intoxication caused by drugs or alcohol misuse

Someone with such an impairment is thought to be unable to make a decision if they cannot:

- understand information about the decision
- remember that information
- use that information to make a decision
- communicate their decision by talking, using sign language or any other means

How capacity is assessed

As capacity can sometimes change over time, it should be assessed at the time that consent is required.

This will usually be done by an appropriately trained and experienced healthcare professional who's either:

- recommending the treatment or investigation

- involved in carrying it out

If the healthcare professional feels you have the capacity to give your consent, your decision will be accepted and your wishes will continue to be respected, even if you lose capacity at a later stage.

If the healthcare professional feels you do not currently have the capacity to give consent and you have not made an advance decision or formally appointed anyone to make decisions for you, they'll need to carefully consider what's in your best interests before making a decision.

Respecting personal beliefs

If someone makes a decision about treatment that other people would consider to be irrational, it does not necessarily mean they have a lack of capacity, as long as they understand the reality of their situation.

For example, a person who refuses to have a blood transfusion because it's against their religious beliefs would not be thought to lack capacity.

They still understand the reality of their situation and the consequences of their actions.

But someone with anorexia who's severely malnourished and rejects treatment because they refuse to accept there's anything wrong with them would be considered incapable.

This is because they're regarded as not fully understanding the reality of their situation or their consequences.

Determining a person's best interests

If an adult lacks the capacity to give consent, a decision about whether to go ahead with the treatment will need to be made by the healthcare professionals treating them.

To make a decision, the person's best interests must be considered.

There are many important elements involved in trying to determine what a person's best interests are.

These include:

- considering whether it's safe to wait until the person can give consent if it's likely they could regain capacity at a later stage
- involving the person in the decision as much as possible
- trying to identify any issues the person would take into account if they were making the decision themselves, including religious or moral beliefs – these would be based on views the person expressed previously, as well as any insight close relatives or friends can offer

If a person is felt to lack capacity and there's nobody suitable to help make decisions about medical treatment, such as family members or friends, an independent mental capacity advocate (IMCA) must be consulted.

Involving the Court of Protection

In situations where there's serious doubt or dispute about what's in an incapacitated person's best interests, healthcare professionals can refer the case to the Court of Protection for a ruling.

This is the legal body that oversees the operation of the Mental Capacity Act (2005).

Situations that must always be referred to the courts include:

- sterilisation for contraceptive purposes
- donation of organs or regenerative tissue, such as bone marrow
- withdrawal of nutrition and hydration from a person who's in a permanent vegetative state or minimally conscious state

Changes in capacity

A person's capacity to consent can change. For example, they may have the capacity to make some decisions but not others, or their capacity may come and go.

In some cases, people can be considered capable of deciding some aspects of their treatment but not others.

For example, a person with severe learning difficulties may be capable of deciding on their day-to-day treatment, but incapable of understanding the complexities of their long-term treatment.

Some people with certain health conditions may have periods when they're capable and periods when they're incapable.

For example, a person with schizophrenia may have psychotic episodes when they cannot distinguish between reality and fantasy, during which they may not be capable of making certain decisions.

A person's capacity can also be temporarily affected by:

- shock
- panic
- extreme tiredness (fatigue)
- medication

Advance decisions and power of attorney

If a person knows their capacity to consent may be affected in the future, they can choose to draw up a legally binding advance decision, also known as a living will.

This sets out the procedures and treatments that a person refuses to undergo.

You can also choose to formally arrange for someone, often a close family member, to have lasting power of attorney (LPA) if you wish to anticipate your loss of capacity to make important decisions at a later stage.

Someone with LPA can make decisions about your health on your behalf, although you can choose to specify in advance certain treatments you'd like them to refuse.

Full Article: https://www.nhs.uk/conditions/consent-to-treatment/capacity/

Digital inclusion and people with learning disabilities

The digital inclusion of people with learning disabilities is an important topic because more of our lives are spent using technology and being online.

3.1 The increasing digital inclusion of people with learning disabilities

The use of digital technology is evidenced across many areas of life for those with learning disabilities (Castro et al., 2023; Caton et al.; Chadwick et al., 2023; Danker et al., 2023), for example, 'social activities, work, support, productivity, navigation and entertainment' (Danker et al., 2023). Digital inclusion-focussed research and practice relating to people with disabilities have proliferated, in part stimulated by the COVID-19 pandemic (Castro et al., 2023; Caton et al., 2023; Chadwick et al., 2023; Engwall, 2023; McCausland et al., 2023; Seale, 2022). This is heartening to see given the increased reliance of government and societal providers of services on technology. Nonetheless, it is important that all stakeholders are able to access the available resources and information about digital inclusion and participation. This includes researchers, policymakers, those providing support, and, most importantly, people with learning disabilities. Hence, as Seale indicates in her response to the review of her technology toolkit (Seale, 2021), a repository of available knowledge, guidance and resources, curated by people with learning disabilities and their allies is an important future step for the field. It is essential that the impetus to promote equality of digital opportunity for people with learning disabilities is not lost as we go beyond the pandemic (Seale, 2022).

In the survey study by Caton et al. conducted during the COVID-19 pandemic, carers of people with PMLD provided evidence suggesting that this group is less digitally included than others with learning disabilities, with only around half being online and using video-conferencing software for social contact. Carers found ICT useful but not all wished to continue using it beyond the pandemic. McCausland et al., 2023 report that, for older adults with learning disabilities, with increased use of technology came both increased negatives and positives during the pandemic. This demonstrates that technology use is rarely simple in terms of its influence on well-being and the heterogeneity of digital inclusion experiences across people with learning disabilities.

Contributing papers (e.g., Castro et al., 2023; Engwall, 2023) also noted that some people with learning disabilities remain digitally excluded, advocating for the need to reach out to these people to ensure that they are not left behind or left out as ICT use proliferates. Others were excluded due to systemic inaccessibility, legal and protective concerns that led to gatekeeping and exclusion (e.g., Engwall, 2023). Engwall highlights that visibility in online spaces may facilitate future digital inclusion. Challenging restrictive practices and inequity of opportunity is a fundamental research and advocacy endeavour.

3.2 The importance of digital skills

Digital skills became more important during the pandemic (see e.g., Castro et al., 2023; Chadwick et al., 2023), with those who had greater need, motivation and existing skills being more successful in moving to online life. Education and training (Danker et al., 2023; Chadwick et al., 2023; McCausland et al., 2023) are all important facilitators of digital inclusion, which can enable people with learning disabilities to develop their digital literacy skills, communication and leadership skills and their confidence in using technology along with supporting others to use ICT. The use of accessible online learning programmes to develop nondigital assertiveness skills is also considered (Fitzpatrick & Trninic, 2023). With the increase in hybrid work in practice and access to education through online programmes, it is essential to enable equity of opportunity for people with learning disabilities.

3.3 Online social contact, capital and connection

One of the primary uses of ICT and the internet is for social contact—to develop and maintain social relationships and to create a sense of belonging and community. People with learning disabilities regard this as valuable and important (Agren et al., 2023; Castro et al., 2023; Chadwick et al., 2023; McCausland et al., 2023; Spassiani et al., 2023) as do those providing support (Caton et al., 2023; Seale, 2022). The unfamiliar and less desirable nature of online compared with face-to-face interaction is highlighted in a number of the papers (e.g., Castro et al., 2023; Caton et al., 2023; Chadwick et al., 2023), particularly those focussing on digital inclusion during the pandemic. Alongside this, accessibility and convenience were great benefits of using technology, in both everyday life and research work (Castro et al., 2023; Caton et al., 2023; Chadwick et al., 2023; Danker et al., 2023). As such, technology continues to embed itself in our 'hybrid' lives. How this operates in relation to social capital, loneliness and isolation, and activity and learning for people with learning disabilities is an important question to consider moving forward.

3.4 Support for ICT use

The importance of support for digital inclusion is evident across a number of papers in the special issue. Many people with learning disabilities still rely on support from family, paid staff and peers to access ICT (e.g., Agren et al., 2023; Caton et al., 2023; Chadwick et al., 2023; Seale, 2022). People with learning disabilities can experience significant challenges in accessing support (Agren et al., 2023; Chadwick et al., 2023; Engwall, 2023; Seale, 2022) that leads to increased digital exclusion. Support from the staff was more successful when it took a holistic approach to people's everyday lives (Engwall, 2023). By being 'possibility focussed', that is, creative, resilient, sharing decision-making and managing risk, digital inclusion has been facilitated by those providing support (Seale, 2022). Future research needs to continue to consider the ways in which support is provided and the opportunities people with learning disabilities have to demonstrate their leadership and support skills. Peer support from existing networks was a preference that emerged within some of the studies (Agren et al., 2023; Castro et al., 2023; Chadwick et al., 2023).

3.5 Challenges and barriers

Across many of the studies, barriers to using and accessing technology were evident (Agren et al., 2023; Caton et al., 2023; Chadwick et al., 2023; Danker et al., 2023; Engwall, 2023; Seale, 2022). Barriers related to technology included cost, the relative amount of inaccessible software and its complexity. People with learning disabilities and their supporters also experienced difficulties in identifying, accessing and using information online (Agren et al., 2023) and found the volume of applications overwhelming (Chadwick et al., 2023). Seale, 2022, in gathering the views of people from various support roles, identified cost, accessibility and environmental factors as key barriers to digital exclusion.

3.6 Digital exclusion and online safety

Awareness and management of online risks (Castro et al., 2023; Danker et al., 2023; Seale, 2022) can be an important prerequisite to digital access. Concerns about safety are also evident in the findings from Chiner et al, 2023. When investigating the perceptions of special educational needs and mainstream teachers, they found that the internet is still viewed as an unsafe place for young people with learning disabilities. They also noted the importance of honouring the human rights of people with learning disabilities to make their own decisions and mistakes.

Full Article: https://onlinelibrary.wiley.com/doi/10.1111/bld.12530

Increasing use of communication in digital technology in health and social care

The use of digital technology in health and social care can improve quality, efficiency and patient experience as well as supporting more integrated care and improving the health of a population.

Digital transformation in the NHS

Supporting your digital transformation journey

How, where and when patient care is given is changing. There is a natural evolution towards smart healthcare services, where technology is embedded across clinical pathways and the digital patient is the new normal. It is vital that our NHS health services, staff and patients are ready for this. Because ultimately, smarter healthcare means better quality, more efficient and safer patient care.

At CCS, our technology experts are here to help you embrace your trust's digital transformation journey, and develop a robust technology procurement strategy.

We've put together a step-by-step guide to buying digital transformation solutions in the NHS. We explore the 3 main phases, with a clear breakdown of the programme stages and projects you will go through along the way.

This guide will help your procurement and ICT functions collaborate effectively. It outlines how to achieve value for money through your procurements and deliver against integrated care system needs, all whilst keeping social value, sustainability and carbon net zero agendas front of mind.

What is digital transformation in the NHS?

aims to use technology to help health and care professionals communicate better and enable patients to access the care they need quickly and easily, when it suits them.

From websites and apps that make care and advice easy to access wherever you are, to connected computer systems that give staff the test results, history and evidence they need to make the best decisions for patients, technology can support improvements in patient care.

For many trusts, the COVID-19 pandemic has driven the need for remote access to healthcare services for patients. Indeed, the expansion of virtual wards will create the equivalent of 5,000 additional beds. Digital transformation is also required to support workforce recovery and staff wellbeing by creating an integrated environment across the care system. This gives health care professionals more confidence and time to care.

What is smart healthcare?

For healthcare to be smart, technology needs to be embedded at each point of the patient's clinical pathway. Not just for the patient, but for staff too. This includes all the equipment used, and the buildings themselves where the care is given.

Smart healthcare services lead to:

- more efficient operations including optimisation of back office systems and the electronic patient record
- better designed clinical pathways that improve patient flow and clinical outcomes
- reduced hospital visits through early intervention and continuing healthcare in a patient home or community setting, with remote monitoring by healthcare professionals.

Unlock the power of digital transformation

With our diverse range of technology commercial agreements and category expertise, we're best placed to help you buy the right technology solutions for your needs at each stage of digital transformation.

We can help you deliver your digital transformation procurement strategy for a truly integrated care system, with interoperability between computer systems and vital patient information at point of care. Our technology categories cover:

- Technology Products and Services
- Digital Future
- Cyber Security
- Software
- Network Services
- Memorandums of Understanding

Full Article: https://www.crowncommercial.gov.uk/products-and-services/technology/digital-transformation-in-the-nhs?gclid=dcf95bb14ae1175f5be33d120d608cd0&gclsrc=3p.ds&msclkid=dcf95bb14ae1175f5be33d120d608cd0&utm_campaign=Generic%20-%20Healthcare&utm_content=Digital%20Transformation&utm_medium=cpc&utm_source=bing&utm_term=healthcare%20tech

New communication methods help to reduce anxiety

Providers should meet the five 'good communication standards'

As set out by the Royal College of Speech and Language Therapists, as set out in the appendix.

5 Good Communication Standards

1. There is good information that tells people how best to communicate with me.
2. Staff help me to be involved in making decisions about my care and support.
3. Staff are good at supporting me with my communication.
4. I have lots of chances to communicate.
5. Staff help me to understand and communicate about my health.

https://www.rcslt.org/wp-content/uploads/2022/02/5-good-communication-standards-RCSLT-Northern-Ireland-Hub-webinar-Nov2021.pdf

Easy Read: https://www.rcslt.org/wp-content/uploads/media/Project/RCSLT/5-good-comms-standards-easy-read.pdf

Inclusive language communication training involves the following skills and strategies

What is inclusive communication?

Inclusive communication is an approach to communication which enables as many people as possible to be included in that interaction.

This approach:

- Recognises that all human beings use many ways of understanding and expressing themselves.
- Encourages, supports and enables people to use whatever ways of understanding and expressing themselves which they find easiest.

It does not relate only to a specific activity for a particular group. It is an overarching approach which is relevant to:

- Everyone and in all situations, not just people with communication support needs.
- All communication at individual, organisation and population levels.
- All modes of communication – face-to-face, telephone, written, online.

Related pages

- Public health
- Aphasia
- Dementia
- Learning disabilities
- Mental capacity and supported decision-making

https://www.rcslt.org/speech-and-language-therapy/inclusive-communication-overview/

An introduction to communication and people with a learning disability

With over half a million adult social care workers supporting people with a learning disability and/or autistic people in England, it’s vital that adult social care workers have the right skills and knowledge to provide high quality, person-centred care and support.

The Core Capabilities Framework for supporting people with a learning disability sets out the skills and knowledge that health and social care workers need to deliver high-quality care and support.

National Institute for Health and Care Excellence (NICE) guidelines can also help you plan support and identify what learning and development your workforce needs.

Explore the adult social care workforce supporting people with learning disabilities and/or autistic people, using data from the Adult Social Care Workforce Data Set.

Supporting people to have meaningful relationships guide

This guide helps employers to think about how they can develop their workforce to identify what carers need to understand about personal relationships and how they can create a workforce development programme.

The Oliver McGowan Mandatory Training on Learning Disability and Autism

Following Oliver McGowan's death, in November 2019 the Government published 'Right to be heard' its response to the consultation on proposals for introducing mandatory learning disability and autism training for health and social care staff.

The response included a commitment to develop a standardised training package that aims to make sure staff working in health and social care receive learning disability and autism training, at the right level for their role which Skills for Care and HEE are co-ordinating the development of.

For any enquiries please email us or HEE. Visit the Health Education England website to find out more about Oliver's campaign, the trial partners, what the training looks like, FAQs and stakeholder feedback.

Find further information from Skills for Care about the Oliver McGowan Mandatory Training.

Identifying workforce learning and development needs examples

These examples are based on real-life scenarios of people with a learning disability and/or autistic people, who display or are at risk of displaying behaviours which challenge.

They're for adult social care commissioners and providers, to help you identify learning and development needs and plan support. you can use these examples to create your own plan for the person being supported. Download the 'Plan template' and 'How to use the examples overview' for further guidance.

https://www.skillsforcare.org.uk/Developing-your-workforce/Care-topics/Learning-disability/Learning-disability.aspx

Good learning disability and autism training

At Skills for Care, we take the position that good quality training in either learning disabilities, autism or both should involve the following elements.

- Each employer must decide on the level of training needed for each member of staff according to their role and previous learning.
- The training should be structured to use the two Core Capabilities Frameworks which are in three tiers:

Tier 1: People who require a general understanding of autism and/or learning disability and the support autistic or learning disabled people may need.

Tier 2: People with responsibility for providing care and support for a person with a learning disability and/or an autistic person or people, but who could seek support from others for complex management or complex decision-making.

Tier 3: Health, social care and other professionals with a high degree of autonomy, able to provide care and support in complex situations and/or may also lead services for people who have a learning disability and/or autistic people.

- Training should include interactive learning where the learner can consider how to apply their learning in their specific role.
- The training should include input from people with lived experience, ideally by being delivered by people who are autistic and / or have a learning disability.
- The Oliver McGowan Mandatory Training on Learning Disability and Autism covers all of tier 1 of both frameworks and some carefully selected items from tier two – the ones that everyone needing tier 2 will need. It’s one way that an employer could meet or partly meet their staff’s training needs.

https://www.skillsforcare.org.uk/Developing-your-workforce/Care-topics/Learning-disability/Good-learning-disability-and-autism-training.aspx

The Oliver McGowan Mandatory Training on Learning Disability and Autism

The Oliver McGowan Mandatory Training on Learning Disability and Autism aims to provide the social care and health workforce with the right skills and knowledge to provide safe, compassionate, and informed care to autistic people and people with a learning disability.

Research has shown that on average, people with a learning disability and autistic people die earlier than the general public, and do not receive the same quality of care as other people. Evidence suggests that effective training can bring about changes in the way people work and drastically reduce these inequalities.

The Health and Care Act 2022 introduced a requirement that all CQC registered service providers must ensure their staff have training on learning disability and autism that is appropriate to their role. The Oliver McGowan Mandatory Training on Learning Disability and Autism is the Government’s preferred and recommended training for health and social care staff to undertake.

The Oliver McGowan Mandatory Training has been co-produced, trialled with over 8300 health and care staff and independently evaluated by the National Development Team for Inclusion (NDTi).

The Oliver McGowan Mandatory Training comes in two parts. The first part is an elearning module, and the second part is either an online interactive session (Tier 1) or a face-to-face session (Tier 2). All of the training includes delivery by people with lived experience of a learning disability or of being autistic.

Both parts of the Oliver McGowan Mandatory Training have been added to Skills for Care’s Adult Social Care Workforce Data Set (ASC-WDS) so that employers can record and report on completion rates.

https://www.skillsforcare.org.uk/Developing-your-workforce/Care-topics/Oliver-McGowan-Mandatory-Training/Oliver-McGowan-Mandatory-Training.aspx

Creating a communication supportive environment: Early years

What is a communication-supportive environment?

A communication supportive environment is one that ensures that children's speech, language and communication skills are planned for and supported throughout the day. It will look slightly different in early years settings and in school environments, but in general, it covers three aspects:

- The **physical environment**
- The **strategies** that **adults** use
- The **opportunities** that children have to practise their communication skills

Physical environment

A communication supportive environment in the early years has:

- Cosy quiet spaces that give children a chance to think and talk together.
- Areas for children to engage in role play, creative and messy play, and outdoor play.
- Minimal background noise. Young children are still developing their attention and listening skills and so they find it hard to filter out background noise and tune into listening.
- Resources labelled with pictures and words to help children to be more independent in accessing resources and organising themselves.
- Pictures or photographs so that children can self-register and to let them know the timetable for the day (see our visual supports information).
- Book corners – spaces where children can curl up and share a book with a supportive adult or a peer.
- Clear and consistent routines – how does the environment help children to know what to expect and when?

Adult strategies

The way adults talk to children can have a big impact on the development of their speech, language and communication skills. Key strategies include:

- Following the child's lead and talking about their interests;
- Building on what children say;
- Talking in simple sentences and pausing often;
- Modelling words and sentences that match the child's level.

Have a look at our tips on **supporting babies' early communication skills** and **supporting children's early communication skills** for more information and ideas.

Opportunities for children to practise their communication skills

Finally, a communication-supportive environment means that children have lots of opportunities to practise using their speech, language and communication skills throughout the day. These could include:

- Providing children with props and puppets relating to a story you are reading together so that they can act out events from the story and practise using words and phrases they have heard in the book.
- Structured role play activities facilitated by an adult.
- Planned talking activities during circle time.
- Book sharing activities where children have opportunities to communicate as well as listen.
- Small group work activities.

Reflecting on practice

Take a learning walk around your setting and look at the environment from a child's point of view. Does it make sense? Does it have a variety of different spaces for different purposes and different types of conversations? Are there lots of planned opportunities for children to communicate?

https://speechandlanguage.org.uk/educators-and-professionals/resource-library-for-educators/creating-a-communication-supportive-environment-early-years/

Barriers to Effective Communication for Learning Disability	
	Effective communication is essential in ensuring high quality health care, because communication difficulties are characteristic of people with learning disabilities, the nurse needs strategies that can be used to promote communication and understanding by removing barriers, and developing their skills and knowledge.

Learning Disability: Barriers to Effective Communication

Communication is the act or process of using words, sounds, or behaviours to express ideas, thoughts feelings, or exchange information (Merriam – Webster, 2014).

People with learning disabilities die younger than other people (Heslop et al, 2013). The Independent Inquiry into Access to Healthcare for People with Learning Disabilities (Michael, 2008) followed the Mencap report Death by Indifference (2007). The report concluded that there are inherent risks in the care system that result in high levels of health needs not being met. The inquiry found that people with learning disabilities appear to receive less effective care and that there are many shortcomings in the way treatment is delivered, with avoidable suffering caused by untreated ill health.

Effective communication is essential in ensuring high quality health care (Balandin & Hemsley, 2008) and is an essential skill for nurses (Nursing Midwifery Council (NMC), 2007). Because communication difficulties are characteristic of people with learning disabilities, the nurse needs strategies that can be used to promote communication and understanding by removing barriers, and developing their skills and knowledge.

Why ?

Effective communication is a recurring and pervasive theme in government policies, reports and best practice guidelines (Turner, 2014). Good practice guidance on working with parents with a Learning Disability (Department of Health, 2007), the survey of the human rights of adults with learning disabilities, *A life like any other? (*Joint Committee on Human Rights, 2008) and *valuing people now* (Department of Health, 2009). In particular, *A Life Any Other?* highlights the ways in which barriers to communication can all too easily result in the human rights of people with learning disabilities being breached, unmet communication needs can restrict access to public services. For example, research commissioned by Mencap showed that, of 215 GPs interviewed, 75% had received no training to help them treat people with a learning disability (Taylor Nelson Sofres, 2004, cited in Mencap, 2004).

Children with LD

Regnard et al. (2007) found more than twenty changes in behaviour in children with learning disability when they encountered distress, and it is likely those who have no verbal language are likely to be more receptive to non-verbal communication (Tuffrey –Wijne & McEnhill, 2008). It is therefore vitally important for professionals working directly with children to engage with them however possible.

Adults with LD

Difficulties with communication have been consistently reported as a barrier in supporting adults with learning disabilities at the end of life .

HEALTH NEEDS

A high People with learning disabilities are likely to need assistance in communication. It has estimated that there are 1.5 million people in the United Kingdom (UK) with learning disabilities and between 50% and 90% suffer from sensory loss (Eric et al, 2012). Most people with learning disabilities have greater health needs than those with no disabilities. They are also likely to die at a younger age (Mencap, 2007). A number of reports in recent years have shown that there are failings in accessing services and in providing appropriate treatment for people with learning disabilities(Equal Treatment: Closing the Gap(2006); Death by Indifference (2007)). A life like no other (2007), a report into services for people with a learning disability in England, found that adults with a learning disability are particularly vulnerable to breaches of their human rights in healthcare services.

There is considerable evidence that people with learning disabilities are not receiving the same level of health care as other people. In the UK, there have been many documented examples of secondary health services causing te preventable death of people with learning disabilities, with contributory factors reported to include poor communication, a failure of heath service staff to recognise pain, delays in diagnosis and treatment, a lack of basic care, and the use of Do Not Resuscitate orders (Heslop et al., 2013; Mencap, 2012a). A UK based

Confidential Inquiry into premature deaths of people with learning disabilities (Heslop et al., 2013) estimated that 37% of deaths were potentially avoidable.

When people with learning disabilities use health services, staff may have difficulty in meeting their needs because they are unable to communicate effectively with them. A number of reports (Department of Health, 2008; Mencap, 2012; Royal College of Nursing, 2010) highlighted the communication complexity between patient and the staff which have resulted in some cases of deaths and poor quality hospital care.

HISTORY

A report from Mencap (2007), entitles *Death by Indifference,* highlights the poor treatment received by six people with learning disabilities admitted to acute adult and mental health service. This poor treatment ultimately led to these peoples' deaths. The report goes as far to say that institutional discrimination exists within the National Health Service (NHS) towards people who have a learning disability with them getting worse health care than non-disables people. One of the major concerns raised by Mencap was the notion of diagnostic overshadowing. This is neglecting to recognise signs and symptoms of ill health assuming them to be characteristic of a person's learning disability.

Death by indifference

In 2004, Mencap published *Treat me Right,* a report which highlighted the inequities of NHS healthcare provision to people with learning disabilities. This also highlighted that that healthcare professional should not depend on carers or family to communicate with service users with learning disabilities and hospitals must perform their legal duty of care. Healthcare providers are accountable to make sure that these service users have their needs met and this include an easy-read information in place. In 2006, the Disability Right Commission further emphasised concerns that people with learning disabilities were not afforded equitable access to healthcare services and treatment and as a consequence suffered more ill health and were more likely to die. In 2007, Mencap published *Death by Indifference,* a report which told the shocking stories of six people with learning disabilities who suffered potentially avoidable deaths while in various NHS healthcare service by improving communication. A subsequent independent inquiry (Micheal, 2008) and port by the Local Government Ombudsmen and Parliamentary and Health Service Ombudsmen (2009) both confirmed that people with learning disabilities were consistently being placed at risk within primary and secondary healthcare services due to lack of and staff –patient communication

http://www.ombudsman.org.uk/__data/assets/pdf_file/0013/1408/six-lives-part1-overview.pdf

Death by Indifference (Mencap, 2007) attributed the unacceptable standards if care largely to an ignorance or apathy by nurses and other health professionals to understand and listen to their clients with learning disabilities. It is important that the individual is continually consulted about their care regardless of the extent of their learning disability.

74 deaths and counting (2012)????

The report by Mencap, 2012 relayed details of more potentially avoidable deaths of people with learning disabilities within NHS services.

Reasonable adjustments

The failure of public services to make reasonable adjustments regarding communication not only makes it extremely difficult for people with learning disabilities to access services, but it may also breach the Equality Act (2010) and Article 8 pf the European Convention on

Human Rights (Micheal, 2008, p24). Poor communication with people who have learning disabilities has consequences that range from the relatively insignificant. For example a service user is given coffee when they would prefer tea.

Non Verbal Communication

Non-verbal communication is as important as verbal in interactions that influence dignity. For example, in a study of older people’s transitions (include older people with learning disabilities) between care service, Ellins et al. (2012) noted the following:

‘one of the most striking findings was that even the smallest gestures by providers to connect with somebody as a human being, such as a smile or a hug could make

Makaton

The Makaton language programme is commonly used by people with learning disabilities. Many people with learning disabilities use speech, there are also a range of altranative methods of communication which can be used in conjunction with speech. Sign systems are used widely among people with learning disabilities, either alone or in conjunction with speech. One of the common systems is Makaton(Williams, 2009). However, Hannon (2003) found that no one at the hospital had heard of it. One of the people with a learning disability involved in the study said any of the health care professionals did not understand him.

Easy Read

Some people can benefit from written information being into an easy-read format. This involves the use of simple sentences and language and the use of photos or pictures to support the meaning of the written words. When producing written information for patients, it may be worth considering accessibility for patients who may be non-verbal or have a learning disability. An easy –to –read, information resource with picture and images and dew words can support people with learning disabilities to have a greater understanding of information and support their decision making.

Talking Mats is ‘a visual framework that uses picture symbols to help people with a communication difficulty communicate more effectively’ (Murphy and Cameron 2005, p.3). Using pictures to represent topics and options and a visual scale with people with little or no speech and people who have difficulty in understanding speech can assist them to express their wishes about what will occur in their own life. Service providers, including case managers, can use this tool to help the person with disability consider and discuss a variety of options. The pictures are placed on a mat so that the person with disability can look at the options and choices available and then move them using the visual scale to indicate how they feel about each option. The visual scale might include symbols for liking something, for being unsure and for definitely not liking or wanting something. More complex visual scales can be created, depending on the person’s needs and abilities.

Many people with a variety of disabilities use Talking Mats successfully. Nevertheless, there are some people for whom this system is not suitable. Murphy and Cameron (2005) suggested that to use Talking Mats successfully, the person using the mat must be able to recognise picture symbols and must be able to understand at least two keywords at a time. The person must also have a reliable way of confirming his or her views so that the case manager or service provider can be sure that the placement of pictures on the mat does in fact reflect the person’s views

Person-Centred Approch

Patient- or person- centred approaches to health are increasingly seen as more efficient as they promote good communication between the clinician and patient but research to support this is lacking (Lewin et al., 2009). The Mental Capacity Act (2005) is based on person-centred principles and gives legal backing to previous guidelines for good practice (Mencap, 2010). It gives responsibility to all healthcare professionals to follow person- centred guidance in addressing issues of choice and consent in healthcare with the learning disabled. The key principles of this include the person being at the centre of any planning and discussion. This does not mean decisions are simply taken in their best interests but ways are sought to actively involve them in decision- making using accessible communication systems when necessary.

McCaffery et al. (2010) argues that although there have been major advances in way to increase patient involvement in health decisions, with the benefits of greater involvement and shared decision-making now widely accepted, there has been little attention given to the development of tools and strategies to support participation of adults with lower literacy, who are members of a group with poor health knowledge, limited involvement in health decisions and poor health outcomes. McCaffery et al. (2010) proposed a framework to consider the different stages of shred health decision making and the tasks and skills required to achieve each stage.

The 6cs

In 2012, the Department of Health carried out a widespread consultation exercise on values for nurses, which were published in ‘Compassion in Practice: Nursing, Midwifery and Care staff: Our Vision and Strategy’. The vision is based around six values: care, compassion, competence, communication, courage and commitment. The vision aims to embed these values (the 6Cs) in all nursing, midwifery and caregiving settings throughout the NHS and social care to improve care for patients.

Conclusion

In conclusion, the author highlighted the importance and the barriers of communication when working with people with a learning disability, and the some communication methods that a learning disability nurses can use to work effectively with this client group. Good communication is the basis of effective care provision, and the value of developing a relationship and getting to know the individual demonstrates how this enables effective communication to take place. Health care professionals need to develop competencies in identifying individual communication needs, and developing creative ideas for how to overcome these, using a range of tools to aid communication. Person-centred approaches provide a framework to do this on an individual basis, enable and support people to make choices.

Full Article: https://www.ukessays.com/essays/nursing/learning-disability-barriers-effective-9211.php

Words that blame	
	The language of social care is filled with words that blame people seeking and drawing on support. Our so called ‘strengths-based’ practice drips with deficit-based terms that stigmatise people as problems. Our ‘person-centred’ approaches are infused with phrases that marginalise.

In this blog post I'll explore ten widely used blaming words and phrases, then in part two, I'll consider what this says about our practice, and how we can shift the narrative and move beyond blame.

1. Hard to reach

Labelling individuals and groups as 'hard to reach' implies people are deliberately avoiding contact, keeping their distance, staying away. It places the blame entirely with them. But how hard are we really trying before we slap on that label as a convenient excuse?

Hard to reach? Or easy to ignore?

And couldn't the 'hard to reach' label be just as easily applied to us? Our lack of accessible information and reasonable adjustments. Our jargon and acronyms. Our eligibility criteria. Our thresholds. Our risk assessments. Our waiting lists. Our 9-5, Mon-Fri opening hours. Our city centre offices with security guards on the doors.

We blame individuals and groups for being hard to reach, from behind our impenetrable walls.

2. Refuses to engage

We use the term 'refuse' a lot. Refused an assessment. Refuses services. Refusing treatment.

Refuse suggests defiance, stubbornness. Blaming, again.

What about 'chose not to'? 'Decided against'?

What about some acknowledgement of informed decision-making by the person? Of agency? Of control? What about some evidence of a conversation? Of capacity to decide? Weighing up options? Advocacy? Choice?

Was there any?

And what of the classic 'refuses to engage'? We condemn people for not responding or participating. Not getting involved. But hang on, who exactly should be engaging here? We're public servants – here to serve, not to get people to serve us. We should be focusing on what matters to people, instead of blaming people for not doing the things that matter to us.

"Again look at the question: 'how do we get people to engage?' With respect you don't get ppl to engage. You listen to what they care about enough to act on, and then support them to work with others to do what they care deeply about. It's not about getting ppl to do what we want." **Cormac Russell [1]**

3. Frequent flyers

We blame people for not responding, for not doing what we ask, for not being where we want them to be. And we blame people for being too present. For ringing up too often. For coming back too regularly. For asking too much. 'Frequent flyers'. 'Revolving door customers'. 'High intensity users'.

Behind these derogatory labels are human beings with hopes and fears and worries and aspirations and fluctuating needs for care and support. Are we really listening? Are we really meeting people's needs and supporting them to get on with living their lives? The fact they're coming back again and again suggests not. So, who exactly is to blame here?

4. Carer breakdown

Our statutory guidance requires that we offer an assessment "where it appears that a carer may have needs for support (whether currently or in the future)". That our assessment establishes "not only the carer's needs for support, but also the sustainability of the caring role itself". That we determine "whether the carer is, and will continue to be, able and willing to care for the adult needing care" [2].

Yet when someone is no longer able or willing to continue in their caring role, we're quick to apply the 'breakdown' label.

Indeed, the language relating to unpaid carers is dripping with blame. We're either blaming carers for 'struggling to cope' and 'breaking down' or blaming the person they care for and about by using phrases like 'the burden of caring' and 'respite' – which means 'a pause or rest from something difficult or unpleasant' [3].

'Carer breakdown' (carers aren't cars!), or carers who are exhausted worried isolated ignored lonely confused angry grieving frustrated abandoned desperate scared just trying to do their best for the people they love – or don't love – and facing so many too many hoops to jump through, forms to fill in, boxes to tick, phone calls to make, battles to fight.

'Carer breakdown', or carers we've failed to identify and listen to and support?

5. Bed blockers

'Bed blockers'. Such a hideous, dehumanising term applied to people who are 'medically optimised' and no longer meet the 'criteria to reside' but can't be discharged from hospital for any number of reasons – usually nothing to do with the needs and wishes of the person, and everything to do with failures in communication and coordination in the wider 'system'.

This is the language of widgets and processes and targets and flow, not of compassion and humanity.

6. Challenging behaviour

The 'challenging behaviour' label is, well – challenging.

The phrase labels the person's behaviour as problematic, as something that must be controlled or managed so the person behaves more 'appropriately'. But who defines what is 'appropriate'?

"Somebody has decided that my behaviour, or the person's behaviour, needs to be modified. Needs to be improved, mainstreamed, made less extreme. So, there's a power differential right there, isn't there? And the person's agency to behave in the ways that are most comfortable for them is taken away".

Alexis Quinn [4]

'Problems' require solutions, and too often having identified 'challenging behaviour', our response is to increase medication or restriction or restraint. Separation. Seclusion. The classic medical model of treating and fixing rather than understanding what's happened to – and what's happening around – the person.

All behaviour is a form of communication. If I suggest your behaviour is ‘challenging’, I’m either failing to understand – or deliberately ignoring – what you’re communicating, and why. Maybe you’re scared? Excited? Frustrated? In pain? Angry? Bored? Lonely? Hungry? Sad? Maybe something has happened or there’s something going on around you that’s causing you to lash out or to retreat? Maybe it’s my behaviour that’s challenging you?

Even when we do acknowledge the communication element of a person’s behaviour, we still manage to twist this to blame the person, whose ‘challenging behaviour’ is attributed to *their difficulty* in communicating what they’d like or need – not our failure to meet their communication needs, and in turn their human rights, and our legal duties.

And no, ‘behaviour that challenges’ or ‘behaviours of concern’ aren’t any better, because they’re still loading blame onto the person. And while referring to ‘distressed behaviour’ (hopefully) shifts the focus to understanding the reason for the distress and (hopefully) prompts some wider changes to relieve it, it’s still a label. And anyway, maybe the person isn’t communicating distress at all.

“I can remember meeting an Afro-Caribbean man having treatment on a mental health ward. He told me that one day he was starting to feel better, so he started singing loudly in the corridor. For him this was an expression of joy. But in reserved Britain, staff interpreted this as unusual behaviour and upped his medication.”

Claudia Hammond [5]

7. Non-compliant

Compliant means obedient. Submissive. Biddable. It means you do what you’re told. You do what is expected of you, what somebody else thinks you should be doing. So, if we label you as ‘non-compliant’, we’re effectively saying you’re not doing what we want you to do. Because we know best. Obviously.

8. Complex

Complex cases. Complex individuals. Complex health conditions. Complex lives.

Real lives *are* complex. Messy. Rainbow coloured crayon scribbles on crinkled and torn pages. Stuff happens – or doesn’t. Too much. Not enough. Stops. Starts. Loops back. Dead ends. Creeping, miniscule shifts. Rapid, devastating changes. Balancing. Juggling. Waving. Falling. Drowning.

Real lives don’t fit the straight lines of our ‘system’, the black and white boxes on our forms. Our processes and pathways require a single label at the start. One ‘primary support reason’. One ‘service user group’. Go.

Too many labels = too many boxes ticked = too many pathways = too many professionals = too many conversations = too many options = too much time = not enough time = not enough options = ‘complex’.

And then often, ‘too complex’.

Of course, ‘complex needs’ is the classic. We’ve even built complexity into the term ‘complex needs’, as the multiple references in the Care Act statutory guidance illustrate. “Multiple and complex needs”. “Highly specialised and complex needs”. “Less complex needs”. “More complex needs”. “Particularly complex needs”. “Higher or more complex needs”. “Complex ongoing healthcare needs”. “The most complex needs”. “Multiple complex needs". "Complex SEN and care needs". "Complex health and care needs". "Complex care needs". [6]

The guidance contains several case studies, including 'Isabelle' who 'is 15 years old with complex needs' and Maureen who "is 72 years old.. with complex care needs'. We don't find out what their needs are, just that they are 'complex'.

Like 'challenging' and 'vulnerable', 'complex' is a meaningless term – used repeatedly to convey – well, what exactly? Yes, people's lives may be complicated, but people's basic needs are simple. Somewhere to call home and to belong. Someone to love, and to be loved in return. Something to do. Something to look forward to.

Stop using labels as excuses.

9. Difficult

"What starts as a note stating I cried in an appointment, becomes a letter that details a "difficult appointment", which takes flight as a descriptor of me as a "difficult person", which ultimately leads to a doctor I only just met describing me as "difficult – as expected."

Wren [7]

Tricky discussions. Feedback we find hard to hear. People experiencing tough times. Difficult conversations and difficult situations quickly morph into just plain 'difficult'… and yes, it's pretty much a catch all term for all the other blaming words and phrases listed here too.

Difficult case. Difficult service user. Difficult customer. Difficult patient. Difficult family.

Labels stick.

10. Vulnerable

And finally, the v-word. Although I've already written at length about the term 'vulnerable', it's worthy of a mention here – partly because it's so ubiquitous, but mainly because it points the finger squarely at the person as the problem and stops any consideration of the external factors that make people vulnerable. And in turn this prevents any focus on – or attempts to change – the situations or circumstances that create vulnerability.

During the pandemic we've seen a further sinister step. Not just blaming people for being vulnerable, but in turn blaming 'the vulnerable' for 'restrictive' (protective!) measures, with tweets like "quarantine the vulnerable – let the rest of us live our lives" and "vulnerable people can just stay inside! Why should the rest of us wear masks??!!" and newspaper headlines including "Boris Johnson speaks of 'heavy heart' as Christmas is sacrificed to protect the vulnerable." [8]

Such a divisive and dangerous narrative.

These blaming terms demonstrate and perpetuate the 'them and us' divide that pervades our practice.

We know that connection and relationships must be at the beating heart of our better, brighter social care future. And we also know that blame destroys trust, stifles curiosity and sabotages relationships.

So how do we shift this narrative?

How do we move beyond blame?

Part two: Beyond blame

https://rewritingsocialcare.blog/2022/04/23/blame/https://rewritingsocialcare.blog/2022/04/23/blame/

Beyond blame

As I discussed in my previous blog post, the language of social care is filled with words that blame people seeking and drawing on support.

'Hard to reach'. 'Refuses to engage'. 'Frequent flyers'. 'Carer breakdown'. 'Bed blockers'. 'Challenging behaviour'. 'Non-compliant'. 'Complex'. 'Difficult'. 'Vulnerable'. And many more.

These terms don't just feature in our conversations and records. We recruit social workers to work with "non-engagers", "the most complex and challenging adult cases" and "some of society's most vulnerable individuals" [1]. We have policies for 'dealing with difficult families' and guidance on 'engaging hard to reach groups'. We have 'Complex needs teams' and 'Challenging behaviour units'. And in the wider world, this language features in news headlines ("Operation Re-set' launched in south east to clear bed blockers' [2], "Carers struggling to cope during the pandemic" [3]) and government press releases ("£2.9 billion funding to strengthen care for the vulnerable" [4]).

The irony of course is that so many of these blaming words and phrases can just as easily be applied to 'service land'. Hard to reach? Yep. Challenging behaviour? Oh yes. Difficult? Sure. Complex? Absolutely.

"During one of the first conferences I'd been asked to speak at, the person before me spoke of the 'challenging behaviour' of people with dementia. It made me so sad that I quickly took a pen from my bag and rewrote a section of my speech to talk about the challenging behaviour of healthcare professionals, whose ignorant response distresses us."

Wendy Mitchell [5]

The language we use reflects our attitudes and influences our behaviours. So, what does this blaming language tell us about our current practice?

Labels close minds. Once applied, they stick, and lead to assumptions and prejudgements. These terms become not just part of the person's record, but part of their identity. Become their identity.

"After a while, it feels as if you actually cease to exist, swamped by this paper version of yourself which somehow takes on its own life. After a while, it is your "paper-self" who is risk assessed, diagnosed, and treated. After a while, you realise there's nothing you can do to stop the rise of your paper-self, because every word, every action, every movement you make only adds to its ever-growing and everlasting presence."

Wren [6]

If we hear or read labels like 'frequent flyer', 'difficult', 'complex' or 'challenging' before we've even met someone, our response is pre-loaded with assumptions linked to previous encounters, meaning we fail to properly listen or observe or understand what's happening now, and why.

And in turn our failure to listen or observe or understand leads to solutions and fixes that don't address the underlying causes, which can have devastating consequences – particularly when behaviour we treat as challenging is actually an expression of pain.

"Imagine feeling severe pain and not understanding what is happening, nor even being able to ask for help and information. That is frequently the case for people with profound learning disabilities who cannot communicate verbally. Yet when distress and anxiety alter their demeanour, it is often dismissed as 'challenging behaviour' until the illness causing the pain reveals itself in some other way."

Jenny Morris [7]

Labels like 'vulnerable' prevent us from acknowledging and addressing the circumstances and policies and attitudes and power imbalances that create and perpetuate vulnerability – and may prevent people seeking support too. And terms like 'difficult' undoubtedly prevent people from raising concerns – not just for fear of being stigmatised, but also for fear of care and support being removed.

Describing people as 'non-compliant' exposes our fixed expectations about what 'should' be happening and the 'we know best' power dynamic. 'Carer breakdown' and 'bed-blockers' shifts attention from the failures of our services and support. And terms like 'hard to reach' or 'refuses to engage' make it easy for us to walk away.

These blaming terms demonstrate and perpetuate the 'them and us' divide that pervades our practice.

We know that connection and relationships must be at the beating heart of our better, brighter social care future. And we also know that blame destroys trust, stifles curiosity and sabotages relationships.

So how do we shift this narrative?

How do we move beyond blame?

From blame to accountability

"One of the most insidious ways in which institutions maintain their power to continue to fail is through their tendency to blame individuals for institutional failings. This is woven into public service language.'

Alex Fox [8]

When something doesn't turn out in the way we hoped or expect, instead of asking why, we ask who? Whose fault is it? Who can we blame?

There's some element of failure behind every one of the blaming words and phrases I've mentioned. While we're busy blaming people for failing to show up or cope or behave, we're fundamentally missing the basic point that the failure lies with us. Failure to ask, and understand, and do, what matters most to the people we serve. Failure to identify, listen, empathise, and respond compassionately. Failure to relinquish power and control. Failure to comply with our statutory duties and uphold people's human rights.

Failure to acknowledge where and how and why we're failing.

Accountability is essential, but that doesn't mean we shift the blame and start pointing fingers at colleagues. The blame culture is already far too prevalent and damaging within our organisations. It also doesn't mean we blame 'the system' – because – well, we *are* the system. And it definitely doesn't mean we add more tick boxes to our forms to justify our every move. It means we know and follow the law, we're transparent about our responsibilities and we're honest about our mistakes and where we need to do better. We acknowledge that we're still learning, and we welcome – and act on – suggestions about how we improve.

From furious to curious

Blame prevents curiosity, and learning, and change.

Next time you hear or read one of these blaming words or phrases, or say or write one of them yourself, question the label. Then look beyond it, and see and hear the person. Ask yourself what's really going on here? And why? What's happened – or happening – to this person? What are they communicating? What's important to them? What would they like to happen next?

Be aware of the impact of your own behaviour and question your response. What does it say about your own attitudes and assumptions? And in turn what does that tell you about the expectations and operation of the wider system? About where the power and control really lie?

We blame people when things don't turn out as we expect and when things don't go to plan. But whose expectations are these? Whose plan are we following?

Whose needs are we really meeting?

From correction to connection

We have to shift our focus from correction to connection. Move from trying to mould people to 'fit in' – to 'engage', 'behave' and 'comply' – to meeting people where they're at, and on their terms. Understanding and accepting and being interested in and caring about people for who they are, and want to be, not who we think they should be, or how we think they should behave.

No assumptions.

No judgement.

No blame.

https://rewritingsocialcare.blog/2022/04/23/beyond-blame/

Labels

Let's talk labels. At this time of year, there are lots around. Labels glued to boxes containing purchases made online. Labels taped to packages and sent off in the post. Labels tied to presents underneath the tree. Labels attached to jars of mincemeat and chutneys and jams. Labels fixed to suitcases as people travel home, or away, for Christmas.

And so it should be. Labels are for parcels and gifts. Jars and suitcases. They describe a destination, explain what's inside. They are attached. They stick.

But in social care, our labels are for people. Service user. Case. Customer. Client. Self-funder. Full-fee payer. Carer. Cared-for. Expert by experience. Referral. Inappropriate referral. Challenging. Difficult. Complex. Vulnerable. Frail. LD. PD. Eligible. Not eligible. Non-compliant. Resistant. Avoidable admission. Bed-blocker. Frequent flyer. Optimized. Activated.

And like labels on parcels and gifts and jars and suitcases, our social care labels also describe a destination and explain what's inside. We attach them. And they stick.

Labels open doors

"The search for an accurate diagnosis takes over your life, ultimately knowing that if you have a name for what is wrong, this will give you the passport to the support and services that you need."

Caroline Tomlinson [1]

People usually require a label (eligible, vulnerable, at risk…) to enter our social care world. And once they're in, our labels define their 'journey'. We rely on these labels. Indeed we use them to structure our services and to name our teams (Older Adults, Learning Disability Team, Complex Needs Team..). Without them we're not quite sure which pathway to direct people down, or where to refer them next.

Labels help us process people quickly. They're a handle (literally) we use to pick people (cases) up and move them around our system. Sometimes we add a priority label too – sending people off down a pre-determined pathway, or on to the next stage in a workflow with a rating, a flag, a red/amber/green or a high/medium/low attached.

Individuals and families seeking support learn to adopt our labels too – fully aware that certain terms guarantee entry to 'the system'. A mum ('carer') recently described using the phrase 'complex needs' in relation to her son because she recognised it as a "gateway term" and a "magic word". A way in.

"if you don't use 'their language' on those meetings it makes it more difficult to get support. I regularly use/d language I hate because it has a sort of hyper-functionality."

Katherine Runswick-Cole [2]

Labels close minds

While labels may open doors, they also close minds.

Often we see, and even apply, a label before we've even met the person. And in doing so we attach all our associations and assumptions, and have our standard set of service solutions (4 calls a day, respite, day services, resi) at the ready to fix the problem and meet the need. Then we attach yet another label, describing the person ('referral') as the next stage in our workflow or as the service we're about to prescribe: a safeguarding, a res care, a DOLS, a DST.

When people are given multiple labels, we refer them to multiple teams or organisations. And each of those teams and organisations see the part of the person with the label that matches the name above their door: the need, the problem, the risk, the diagnosis, the condition. Each service screens and assesses according to their entry criteria, and the person gives the same answers to the same questions over and over again. Each team or organisation fixes, treats, manages or maintains a part. Few, if any, see the whole.

"Each service may spend large amounts on 'supporting' the individual, but each is focused on a single set of needs, none able to see all the needs, let alone the whole person."

Alex Fox [3]

And if we struggle to find the right label(s), inevitably we can't quite fit people into an obvious box, so we attach some alternative labels to excuse our failings. Complex. Difficult. Inappropriate referral.

Labels shape identity

"All of these words, all of the nos, all of the labels – the boxes I was put in – became a part of what I believed about myself, what I believed I was capable of, what I believed I could and couldn't do. I became those labels, those words, those NOs. I became small and weak and frail as I withdrew inward, into the shell of my former self."

Joletta Belton [4]

In her book 'Radical help', Hilary Cottam mentions Olive. She suggests that Olive originally gained the label 'housebound' from a visiting social worker "whose job it is to assess the allocation of services". The social worker applied the label to ensure Olive received some support rather than none, and "Olive felt she must describe herself this way to keep the help she genuinely needed".

While we may talk more and more about personalised, 'strengths-based' approaches, the generic labels that emphasise what people can't do and what's wrong remain the ones we apply and the ones that guarantee support.

"What you can't know unless you have #disability is how all the paperwork chips away at your soul. Every box you tick, every sentence about your "impairment" and "needs" becomes part of the narrative of your identity…"

Gill Loomas [5]

Labels also shape the identity of those who attach them. Assessor. Case coordinator. Care manager. Care navigator. Key worker. These 'professional' labels all suggest 'doing to' – reinforcing a power dynamic and leaving no doubt about who really makes the decisions and who is really in control.

Labels dehumanise

As well as shaping identity, labels also deny identity.

By attaching labels like service user, customer and case, we're identifying people not by any of the elements that makes them unique (and human), but by a single factor that makes them the same (and just a little less than human).

These labels also add that bit of distance. Suggest that bit of difference. Dehumanise.

Some time ago, following my suggestion that we describe people as – well – people, a colleague told me that first she'd been told to refer to service users not clients, and now I was asking her to say people instead of service users, and in a few years' time we'd probably find some other term to use instead of people. At the time I was a bit stunned by this. But reflecting on it now, I think it's an indication of that innate desire to separate and group and distance. The assessor and the assessed. The provider and the consumer. The carer and the cared for. 'Us' and 'them'.

We don't just dehumanise people, we dehumanise what people do too. In social care, people don't live in homes, they live in accommodation. Schemes. Settings. Placements. Beds. Units. They don't have a wash, brush their teeth and get dressed – they have personal care. Going to the toilet becomes toileting. Eating is maintaining nutrition. Walking is mobilising. Going out is accessing the community. Going to work is accessing employment. Meeting your mates becomes maintaining relationships. Going swimming is engaging in physical activity.

In the real world we'd describe all of these things as just getting on with our lives, but in social care service land, these 'activities of daily living' demonstrate that people are 'maintaining their independence' and 'achieving their outcomes'.

Labels blame

You over there. You're not just different, separate, not quite human. You're wrong. You've failed. It's your fault. Nothing to do with us.

You didn't meet our entry criteria (we chose not to let you in). You weren't in when we called round (at the time that suited us). You didn't reply to our letter (that we assumed you received, and could read and understand). You wouldn't answer our questions (about what's wrong with you). You wouldn't listen (to our solutions). You didn't read our leaflet (about what will happen next on your customer journey). You failed to follow our rules (about your direct payment). You didn't tell us you weren't happy with our service (we didn't ask you if you were).

Not responding. Not engaging. Not complying. Not communicating in a way we can understand. Not behaving in an appropriate way. Not vulnerable enough. Too vulnerable. Not ticking the right box. Ticking too many boxes. Not fitting neatly in to any service. Not doing what we want you to do.

Not eligible. Non-compliant. Hard to reach. Challenging. Difficult. Inappropriate.

How quickly we apportion blame in the labels we use. How quickly we walk away. Nothing to do with us.

Seeing, and being, the person, not the label - References

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As this very small snapshot of all the academic literature on the subject shows, the search for the perfect 'label' has spanned both decades and continents. There have been numerous surveys and much speculation and debate about the "preferred terms for labelling individuals" in health and social care, and "what do we call 'them'?" remains an unresolved question.

But it's the wrong question.

We don't need to change the labels. We need to remove them. But we can only do that by radically rewriting social care.

Like sorting offices and baggage handling systems, we rely on labels – precisely because we operate a similar system of screening and sorting and prioritising and processing. We use labels to decide on eligibility, determine pathways and prescribe services. We use labels to distance ourselves from the reality of people's lives, to help us justify the way we 'deal with' people like parcels and suitcases. And we use labels to blame, to shield us from the reality of our collective, institutional failures.

So let's think back to those labels on Christmas gifts. We don't write vulnerable, or user, or challenging, or complex, or case. We write people's names. Or mum. Dad. Granny. Uncle. We attach labels to presents for our daughters, sons, sisters, aunties, grandpas, nephews, granddaughters, friends, neighbours, colleagues… People who matter. People we care about. People we love.

People.

These labels reflect our relationships. How we identify the people close to us. Too often in social care we apply, see and become labels because we're too far removed – physically, emotionally, usually both – from people in the context of their families and their communities and their whole lives.

"Because that's what we're talking about. People. Relationships. Families. Normal stuff. Any other label distances and sets up a "different from the rest of us" dynamic that is not useful."

Mark Neary [6]

For too long in adult social care we've focused on what people can't do: what they struggle with; the challenges they face; the needs they have; the boxes they tick. If we're serious about achieving a better, brighter social care future, we need to stop focusing on labels, and concentrate instead on gifts. On seeing and valuing gifts: who people are, and want to be. What they can do, could do, want to do next. What matters. And on giving our own gifts. Time. Compassion. Dignity. Respect. Honesty. Trust. Humility. Humanity.

By shifting our conversations to focus on what matters, and on thriving and not just surviving, we see humans not widgets. Unique individuals with passions and desires and aspirations. We reclaim our identity as humans not robots. And ultimately we reframe social care: removing the labels of crisis and cost and problems and vulnerable 'others', and telling a very different story. A story of hope. A story about people. A story about all of us.

'I am not a client, a customer, nor a service user. I am not a shirker, a scrounger, a beggar nor a thief.

I'm not a National Insurance number, nor a blip on a screen. I paid my dues, never a penny short, and was proud to do so. I don't tug the forelock but look my neighbour in the eye and help him if I can. I don't accept or seek charity.

My name is Daniel Blake, I am a man, not a dog. As such, I demand my rights. I demand you treat me with respect.

I, Daniel Blake, am a citizen, nothing more and nothing less. Thank you.'

Daniel Blake [7]

Full Article: https://rewritingsocialcare.blog/2019/12/20/labels/

Strategies for Communicating with People with Learning Disabilities

This article introduces just a few of the many ways we can improve the effectiveness of our communications with people with learning disabilities.

Strategies for Communicating with People with Learning Disabilities

7 April 2016

Graham Williamson

Scope

This article introduces just a few of the many ways we can improve the effectiveness of our communications with people with learning disabilities. We will discuss five strategies.

Maximizing the hearing environment

It is estimated that over 40% of people with a learning disability have hearing difficulties. In addition, we know that many people with learning disabilities have undiagnosed hearing impairments and that often their carers/advocates may be unaware of a hearing difficulty. A hearing impairment has the potential to interfere with effective communication. Consequently, if you, or any other professional/carer, have concerns regarding a person's hearing status you can refer them for a hearing check via their physician.

As well as directly affecting a person's ability to hear the speech of others, to discriminate between particular speech sounds and to monitor one's own speech production, a hearing impairment can also affect a person's attention. We all have different levels of attention (short/long) and our ability to attend is typically influenced by what is happening around us and how we are feeling at the time. Being interested in something tends to increase our attention span, whereas worry/anxiety reduces attention levels (e.g. visiting the dentist). In order to ameliorate potential adverse effects of poor hearing and low attention levels, it is good practice to:

- reduce background noise
- face the person you are talking to, so they can see your mouth and face
- use a normal tone of voice
- speak at a normal/average rate, i.e. don't talk too quickly
- use signs, gestures and pictures to back up your speech

Using familiar vocabulary

The collection of words a person or group knows and uses is their vocabulary. Now, when we speak to another person we may use words that are not in the other person's vocabulary, i.e. the words may be largely meaningless unless they are explained.

Take a look at the following, the word *aggranoyed* appears to be an assemblage of 'aggravated' and 'annoyed'. It is a so-called **neologism**, i.e. an invented word or phrase with a newly coined meaning. Neologisms may not be readily decipherable.

Do you know what a **gemini tooth** is? Perhaps you'd only know this if you are a dentist (and most likely an American dentist). Apparently it's a tooth that starts to part and develop two crowns. I didn't know this because this phrase was not in my vocabulary. In fact, the phrase 'gemini tooth' is an example of **jargon**, i.e. specialized vocabulary used by persons in the same work or profession. Clearly, using too many jargon words when communicating with people with learning disabilities (or anyone for that matter) will impede effective communication.

What do you call the sweet dessert? Is it a /skɒn/ (rhymes with the word con) or a /skəʊn/ (rhymes with the word cone)? How you pronounce this will likely be influenced by your **accent**. An accent is the distinctive way an individual/group pronounce speech sounds, words and phrases and which is typically associated with a particular nation, locality, social class, and similar. We need to be aware of how we pronounce certain words when communicating with people with learning disabilities, as the person's ability to generalize (e.g. realize that /skɒn/ and /skəʊn/ refer to the same thing) may be reduced.

In summary, owing to such things as our age, job, level of education, cultural background, and similar, we each have a different vocabulary. Different professions have a jargon that may be exclusive to the profession – certainly, jargon words are less likely to be understood by people who are not familiar with them. If it's necessary that someone understands a particular word then you may need to expose the person to the word beforehand – perhaps through sending relevant literature, phoning a carer to enlist their support in introducing the word, and so on.

Making negatives positive

There can be a tendency for people with learning disabilities to interpret negative phrases positively, e.g. ‘You can’t go home yet’ may be responded to as ‘You’re going home’. So, try to use positive instead of negative phrases: perhaps, ‘You need to stay here for a while’ rather than ‘You can’t go home yet’.

Exercise in making negatives positive

Read the following negatively structured phrases and suggest an alternative positively shaped phrase that may be more readily interpretable for each one.

- You can’t go home yet
- Don’t bite my finger
- You mustn’t forget to clean your teeth
- Don’t talk when the mirror’s in your mouth
- You shouldn’t scrub your teeth sideways

Suggested answers

Negative phrase	Positive phrase
You can’t go home yet	You need to stay here for a while
Don’t bite my finger	Keep your mouth open, Stop biting!
You mustn’t forget to clean your teeth	Clean your teeth everyday
Don’t use too much toothpaste	Use two centimetres / this much toothpaste
Don’t talk when the mirror is in your mouth	You have to be quiet when the mirror is in your mouth - or Be quiet when the mirror is in your mouth
You should not scrub your teeth sideways	Brush gently up and down

Re-framing

Re-framing is a method of changing the meaning of something in order to change attitudes. It helps us look at issues differently, and from several different viewpoints. For example, we can re-frame…

- a problem as an opportunity
- unkindness as lack of understanding
- …etc

Exercise in re-framing

Take a look at the following labels and see if you can re-frame them in order to provide a different, more positive, viewpoint.

- distractible
- impulsive
- overactive

Suggested answers

Here are some suggested answers provided by Melanie Cross (2006):

"Distractible"	Multi-tasker Alert Inquisitive Notices things other people don't
"Impulsive"	Honest, decisive, genuine Will try anything Spontaneous Can think of new ways of doing things
"Overactive"	Energetic Enthusiastic Life and soul of any party Needs less sleep

Distinguishing between metaphorical and literal language

Don't get confused between metaphorical language and literal language: when you say, 'I laughed so loud, my sides split'…well, they didn't really, did they?

> **I've got butterflies in my stomach!**
>
> **I've got a frog in my throat!**
>
> **I've got crow's feet around my eyes!**

I think you get the point – these creatures don't actually live in our bodies, do they? It's another example of how we use metaphorical language on an everyday basis. But beware of using too many metaphors and idioms when communicating with people with learning disabilities. Try to say exactly what you mean. It may seem blunt because we often use metaphorical language to ameliorate the impact of some of the things we want/need to say to people. However, many people with learning disabilities will interpret statements literally.

In general, Inferring can be difficult for people with learning disabilities. The situation can arise when a speaker makes an inference rather than saying exactly what they mean, e.g. *I'm thirsty* instead of *I'd like a drink please*. Inference is often used when giving difficult information in order to reduce its impact. However, a person with a learning disability may not grasp the intended meaning. So, avoid using too many inferences: say what you mean even if this seems blunt.

Full Article: https://www.sltinfo.com/strategies-for-communicating-with-people-with-learning-disabilities/

The Language of Dementia – Using Positive and Supportive Words

Language is powerful. More powerful than most people recognise. Not only does it serve as a communication tool, but it also frames our cultures and our beliefs. The vast majority of people simply don't know how we should talk about certain topics and are genuinely surprised when they realise they have made a faux pas. Only by educating people in what words they should and should not use can we help to effect change, not only in the way people talk about dementia, but also in the way the wider community thinks about it.

We love this quote from a report written by the Alzheimer's Society:

"After all, the words we use affect the way we think, and the way we think affects how we behave. The language we all use has the power to impact the lives of millions of people around the country."

By ensuring the language used to talk about dementia is correct, we can work towards putting an end to the stereotypes, stigmas and myths that also surround it. While dementia is life-changing, and can be challenging and stressful for those living with the condition and those supporting them, we truly believe people don't have to languish with dementia, so we want to hear positive, inclusive language used that empowers, respects, values and treats people with the dignity they deserve.

People with dementia aren't victims

We have to remember that each person living with dementia is an individual with a history, a personality, a character – they are not defined by dementia. Instead of talking about someone with pity, referring to them as 'sufferers' or 'victims', we should use more positive terms that state the facts, such as:

- A person living with dementia
- A person affected by dementia
- A person with dementia

And remember, depending on what stage of dementia the person is at, you can always ask them what they prefer. And, given that there are different forms of dementia, people may choose to identify with one specific one, such as Lewy body dementia or vascular dementia.

Dementia is not a disease

Dementia is a set of symptoms caused by diseases that affect the brain. One such disease is Alzheimer's, but there are many more. But dementia itself isn't a disease or an illness, so it shouldn't be referred to as one. Instead, we like to use 'condition'.

Call people people

Sadly, we often hear people living with dementia referred to as 'patients', 'residents' and 'clients'. While these may be appropriate in certain settings such as in hospitals and with solicitors, they shouldn't be used in general terms.

We don't like to hear care homes referring to their 'residents' as it creates a hierarchy and sense of temporary status. We much prefer hearing them talk about the 'people that live with us', which creates a lovely sense of community and inclusivity. At Plan with Care, we avoid using the word 'clients' where possible but rather the 'people we support' or the 'people we work with', as we see it as a collaboration to achieve the best for each individual person.

Distressed, not difficult

When referring to a person who is experiencing a change in behaviour, remember that behaviour is often an expression of needs not being met. Maybe the person is in pain but can't communicate it. So when you refer to the behaviour, use the correct terms…

the person is not being 'difficult', they are 'distressed'. If you do use 'challenging', make sure it's in reference to the individuals finding the situation 'challenging' and not how you're describing the person themselves.

Also avoid labels like 'a wanderer' or 'a shouter'. This is impersonal and, again, omits finding the reason for the behaviour. 'Wandering' gives the idea of strolling aimlessly, when, in fact, a person could be walking about with a purpose that is unknown to you.

You're supporting, not doing

A large part of why we should be careful with the language we use around dementia is that we should always be thinking of how a person feels when they hear what we're saying. Think of the difference between 'John needs feeding' and 'John needs support with eating', or 'Katherine needs washing' and 'Katherine needs a little help with washing'. The second options are much more positive and active and don't passively refer to the person as if they were a child.

The main aims of using the correct language around the topic of dementia are twofold: we empower the individuals living with dementia, putting them first, building self-esteem and including them in the conversation; and we also work to change the view of dementia in the wider community. For people to truly learn about a topic, it has to be talked about in the appropriate way.

Full Article: https://www.planwithcare.co.uk/post/the-language-of-dementia-which-words-you-should-and-shouldn-t-use

Defining the language of care and support

Dr Sam Bennett, Posted on: 10 July 2014 - Categories: Care and support, Guest author, Viewpoint

'Information and advice are among the foundation stones of the Care Act and improving people's access to them is vital to a reformed care and support system,' explains TLAP's Programme Director, Dr Sam Bennett.

Amidst the technical tasks of introducing care funding calculators and preparing for deferred payment agreements, it is easy to underestimate the importance and the challenge of the duty placed upon councils to establish and maintain a universal information and advice service for the local population. But people will have a truly transformational experience of the care and support system when they can access tailored and proportionate information and understand how to navigate their way.

Dr Sam Bennett: "The system can fall down by inadvertently creating an impervious layer of professional language that obscures how things work."

Think Local Act Personal (TLAP) has had an information, advice and brokerage work programme for the past two years. Most recently our steering group co-opted to assist the Department of Health with developing statutory guidance around Clause 4 of the Care Act 2014, so be sure to let us know what you think! Prior to this, TLAP has been developing resources to assist local decision makers and commissioners to better understand the new duty and to make informed decisions about how to go about delivering it.

An early observation made by the steering group (while Andrea Sutcliffe was in the chair) was that language itself can be dis-empowering and exclusive, particularly at the sensitive point in people's care when it needs to be clear and accessible - for example at the stage of hospital discharge or when people with long term conditions are trying to journey through the care and support system. These and many other points in people's lives are where the system can fall down by inadvertently creating an impervious layer of professional language that obscures how things work.

TLAPs response was to develop the Care and Support Jargon Buster which is a plain English guide to the 52 most commonly used social care words and phrases and what they mean. Encouraged by the Plain English Campaign Award 2013, we developed a web based version this year which will expand to accommodate many more terms that need to be brought down to earth. A next step will be to embed the online version of the jargon buster into the websites of councils and voluntary and community sector organisations.

How are we planning to bust further jargon to best effect? By asking people with lived experience of health, care and support as well as those with no prior knowledge to help us of course. TLAP's National Co-production Advisory Group (NCAG) is at the heart of this development and will be making sure all our interpretations make common sense.

Our ambition is to shine a light through the somewhat misted care and support system to make things a little clearer for those relying on it to live a good life.

Full Article: https://socialcare.blog.gov.uk/2014/07/10/defining-the-language-of-care-and-support/

Communication and loneliness

Facts and statistics about loneliness

Loneliness can affect anyone. Experiences of loneliness can vary, but its effects can be profound and wide-ranging. It is considered by many to be one of the largest public health challenges we face.

- In 2022, 49.63% of adults (25.99 million people) in the UK reported feeling lonely occasionally, sometimes, often or always
- Approximately 7.1% of people in Great Britain (3.83 million) experience chronic loneliness, meaning they feel lonely 'often or always'.
- This has risen from 6% (3.24 million) in 2020, indicating that there has not been a return to pre-pandemic levels of loneliness. Read more about the covid-19 pandemic and loneliness.

The latest facts and statistics about loneliness help us to understand more about the risk factors and the impact it can have on different areas of our lives.

By increasing the evidence base, we can help to inform policy and practice to address loneliness.

Overview - Defining loneliness

The definition of loneliness that we use is:

Loneliness is 'a subjective, unwelcome feeling of lack or loss of companionship. It happens when there is a mismatch between the quantity and quality of the social relationships that we have, and those that we want'

This definition draws on Perlman and Peplau's understanding of loneliness. They use the cognitive deficit model, which views loneliness as 'a discrepancy between one's desired and achieved levels of social relations'. This perspective emphasises the significance of *desired* versus *actual* social connections, so it helps us distinguish loneliness from social isolation.

We therefore understand loneliness as an emotional experience: a perceived deficiency in the amount and/or quality of someone's existing relationships.

Types of loneliness

There are different types of loneliness. The following three are the most commonly identified in evidence and literature on loneliness:

- Emotional loneliness – 'the absence of meaningful relationships'
- Social loneliness – a 'perceived deficit in the quality of social connections'
- Existential loneliness – a 'feeling of fundamental separateness from others and the wider world'

Other types of loneliness can include:

- Transient loneliness – a feeling that comes and goes
- Situational loneliness – only occurring at certain times like Sundays, bank holidays or Christmas
- Chronic loneliness – feeling lonely all or most of the time

Social isolation

Loneliness is linked to social isolation but it is not the same thing. While loneliness is an emotional experience, isolation is a lack of social contact.

Loneliness is a subjective feeling, whereas isolation is an objective state. Social isolation is about the 'level and frequency of one's social interactions'. It is defined as 'having few social relationships or infrequent social contact with others'.

Feeling lonely is not necessarily the same as being alone. Some people can spend lots of their time on their own and still feel content. Others may be surrounded by people but feel disconnected from them and lonely.

Loneliness and mental health

Loneliness is not a mental health problem in itself. However, loneliness and poor mental health are interlinked, each can worsen the other and as such, they are closely interlinked. Meanwhile, social connectedness is associated with better mental health.

Poor mental health can lead to loneliness. On the other hand, loneliness can negatively impact mental health. In our Psychology of Loneliness report, we discuss how loneliness and mental health can affect each other, as well as psychological approaches that can help alleviate loneliness.

As well as impacting our mental health, loneliness can affect our physical health. You can read more about the health impacts of loneliness.

Experiencing loneliness

Loneliness is a negative emotional experience. It indicates an unmet need for social connection. People who are lonely might experience unwelcome feelings of isolation, sadness, and disconnection.

According to the UK government's Tackling Loneliness strategy review, reported loneliness is higher for people who:

- are 16-24 years old
- are female
- are single or widowed
- live with a limiting mental health condition
- are renting
- have lower neighbourhood belonging
- have lower local social trust

Experiences of loneliness can differ in their intensity. This can change from moment to moment, over different durations of time, and in different contexts.

Loneliness in the workplace is still quite under-researched, but is important to consider given the amount of time people spend at work. A recent study found that:

- Around 1 in 10 workers feel lonely at work often or always, and nearly half experience loneliness at work some of the time
- Recent changes to working patterns means that 19% of workers now work from home, and 24% are hybrid working. But this doesn't seem to have exacerbated loneliness. Changes in working location during the covid-19 pandemic led to improved relationships for many.
- There is little evidence to suggest that more contact with colleagues leads to less loneliness at work, as loneliness is subjective and distinct from isolation.

Certain factors can increase our risk of loneliness. These include personal characteristics like age, ethnicity, or disability, and circumstances like living alone, going through significant life changes, or living in certain areas. Read more about the risk factors for loneliness.

Impacts of loneliness

We can all feel lonely sometimes. But prolonged and/or intense experiences of loneliness can have negative impacts on our lives. It can affect our health and wellbeing:

- Loneliness can increase the risk of early mortality by 26%.
- Loneliness can put people at greater risk of poorer mental health, including depression.
- There appears to be an association between mental wellbeing and loneliness: research estimates that 60% of people experiencing chronic loneliness experience mental distress, compared to 15% of people who are not chronically lonely.
- 62% of lonely young people say that 'feeling lonely makes them lose confidence in themselves'.

- Research shows that loneliness is associated with elevated blood pressure and acute stress responses.
- Loneliness is associated with ‘poorer sleep quality’ in young adults and ‘sleep inadequacy and dissatisfaction’ in the general population.

And it can also impact our engagement with education and employment:

- Loneliness in early adolescence is associated with lower educational attainment.
- 48% of lonely young people say that feeling lonely makes them ‘less likely to want to progress in work’.
- Higher loneliness levels among employees is associated with poorer work performance.
- A recent study estimates the cost of severe loneliness at around £9,900 per person per year, due to its combined impact on wellbeing, health, and work productivity.
- It has been estimated that loneliness costs UK employers £2.5 billion a year, due to its impact on employee sickness, caring activity, productivity, and voluntary staff turnover.

You can read more about the health impacts of loneliness and the cost of loneliness to our workplaces and economy.

Full Article: https://www.campaigntoendloneliness.org/facts-and-statistics/

Zack’s Story is a short stop-motion animation that United Response created with people they support, to highlight their experiences of loneliness.

Loneliness can affect us all whatever our age or ability. The issues raised in this film are more relevant than ever, now that lockdown and social distancing have changed how we live with and interact with each other.

Loneliness resources:

Discover more about loneliness with Zack's Story – Loneliness - YouTube

The Marmalade Trust: https://marmaladetrust.org/law/

Campaign to End Loneliness: https://www.campaigntoendloneliness.org/

If you need urgent support, please contact the Samaritans:
https://www.samaritans.org/how-we-can...

Stay Connected to Combat Loneliness and Social Isolation

As people age they often find themselves spending more time at home alone. This can affect your health and well-being. Learn if you might be at risk and how to stay connected.

To share the image, right-click on it and select "save image as" to save the file to your computer. We encourage you to use the hashtag #NIAHealth in your social media posts to connect with people and organizations with similar goals.

Stay Connected to Combat Loneliness and Social Isolation

Feeling lonely and being isolated are bad for your health

Try to stay active and better connected if you:

- live alone or can't leave
- feel alone or disconnected
- recently had a major loss
- are a caregiver
- lack a sense of purpose

Ideas for staying connected

Find an activity that you enjoy or learn something new. You might have fun and meet people with similar interests.

Get moving! Exercise decreases stress, boosts your mood, and increases your energy.

Volunteer. You'll feel better by helping others.

Stay in touch with family, friends, and neighbours in person, online, or by phone.

Consider adopting a pet. Animals can be a source of comfort and may also lower stress and blood pressure.

For more information about preventing loneliness and social isolation, visit https://www.nia.nih.gov/health/participating-activities-you-enjoy

You may also be interested in

- Learning more about loneliness and social isolation
- Exploring a social isolation and loneliness outreach toolkit
- Watching a video on combatting loneliness and social isolation

Full Article: https://www.nia.nih.gov/health/loneliness-and-social-isolation/stay-connected-combat-loneliness-and-social-isolation

Feeling lonely and being isolated are bad for your health.

Loneliness and social isolation are associated with higher rates of depression, a weakened immune system, heart disease, dementia, and early death.

Full Article: https://www.nia.nih.gov/sites/default/files/social-isolation-loneliness.pdf

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